When dialogue fails. Music therapy with elderly with neurological degenerative diseases

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In a PhD-research from Aalborg University I have used a mixed method case study design, where I integrated quantitative heart beat measurements and a qualitative hermeneutic analysis on responses given by participants in music therapy. In this paper I am not going to present the research. I will use the opportunity to present one single element from the work. This will be a focus on a clinical strategy for building up music therapy sessions with persons who are gradually losing cognitive abilities and suffer from severe neurodegeneration.

I shall present four levels or steps in the clinical setting, where different strategies are used in order to compensate for missing memory function and missing abilities to communicate. In addition to being part of the doctoral thesis (Ridder 2003), these ideas are based on clinical music therapy work at a geronto-psychiatric unit since 1995. For background information on music therapy with this client group see Aldridge (2000), Brotons (2000), Clair & Bernstein (1990), Fitzgerald-Cloutier (1993), Tomaino (2000), and Wigram et al. (2002).

Neurodegeneration

The client group in this presentation are people who have neurological problems; elderly people where symptoms in the brain are related to symptoms that the person can describe or we, who know the person, can observe. Symptoms related directly to neurodegeneration are here defined as primary symptoms. In this sense, secondary symptoms are symptoms that are not related directly to the changes inside the brain, but related to changes in how these people experience their environment, how their relation to other people is changed, and how they are stigmatized by too little understanding of their illness. Basically, secondary symptoms are related to missing communicative abilities.

My hypothesis is that these secondary symptoms are symptoms that we might be able to change by music therapy, without being able to cure the primary symptoms.

First I want to give a very short introduction to the client group. We have different categories of neurological disorder (Epilepsy, Stroke, Multiple Sclerosis, Developmental neurology) and in this paper the focus is on degenerative diseases. Degenerative diseases are generally associated with Parkinson's disease or Alzheimer's disease. Further more we see Lewy Body diseases, Multi-infarct dementia, Pick's disease, Huntington's disease, Creutzfeldt-Jacob disease, and other degenerative diseases.
Degeneration is seen when something declines or is reduced, and neurodegeneration is seen when a so-called normally developed brain loses function because of pathological disorders in neurons, in supporting glia cells, in neurotransmitter activity, or in recurrent vascular disorders, that are changes in blood supply. Most degenerative diseases are chronic, progressive, and lead to atrophy (Gade 1997). I will not go into details with these different types of damages of brain tissue, but illustrate the degeneration with one example; the formation of plaque. This is often illustrated as small enzyme-`scissors' cutting out certain proteins from the healthy APP-molecules (see picture 13-15 at www.alzheimers.org/ rmedia/graphicshighres.htm ). This gives a formation of beta-amyloid plaque that stick together outside the cell in clumps. These clumps of cell trash disintegrate neurons. At a certain age we might all have small clumps of plaques in our brains. But when the amount increases, and the clumps are seen in certain patterns, then they are markers of a pathological picture, as in Alzheimer's disease.

Most degenerative diseases lead to atrophy. With cortical atrophy brain tissue is shrinking, e.g. when neuronal connections are lost. Atrophy can be located on different kinds of brain mappings, and in this way give some hints of a certain pathological picture.

Atrophy can be focal, located to a specific structure, regional, as on the picture with regional atrophy involving the frontotemporal areas (see picture at: medlib.med.utah.edu/.../ CNS/CNSDG008.html ), or diffuse, causing stray shrinkage, which is seen in vascular dementias.

Metaphorically we can describe the frontal lobes as the conductor of a very big orchestra, or as a net browser that direct us when we net-surfe, or as our decision maker. The frontal lobes are important to empathy, creativity, identity and sociality. But without the orchestra (the other parts of the brain) - or without contact to the orchestra - the conductor will have big difficulties in playing. And without a net bristling with information, there will be nowhere to browse, or no foundation for making decisions (see Goldberg 2001).

The atrophy and the neuronal degeneration are in different patterns markers of different degenerative diseases. Depending on which cortical location and which networking systems are involved, we see primary symptoms where the person experiences problems with perception, executive function, initiating movements, and short-term memory. When areas deeper in the brain - in subcortical areas - are damaged, apathy and depression are very often seen and the person might lose ability to coordinate and time movements and responses, and will have big problems in recalling both recent and remote information (Zillmer & Spiers 2001).

Memory

Our ability to memorize influences all aspects of daily living, even how we `remember forward': how we respond to new experiences and how we plan our day. Before I continue with a short overview on memory function, I want to include a glimpse from a
music therapy session with Mrs F.

Mrs F suffers from frontotemporal dementia (Pick's disease) in an advanced stage. This means that especially frontal lobe and anterior temporal lobe is damaged. The atrophy in her brain might look like the picture with the link above to medlib/WebPath. Mrs F needs help in all activities of daily living. She cannot find her way to her living room or the toilet. She shows symptoms of apraxia and needs help or guidance when dressing or eating. She suffers global aphasia and her language is reduced to a few particular words that she repeats over and over again. Symptoms of amnesia are severe and she does not recognise her sister who is her only relative and to whom she has been very close. Mrs F constantly ambulates. She walks and walks, trying all doors on her way. If her walking is hindered she gets angry and aggressive, and hits staff and peer residents.

In the individual music therapy Mrs F will equally walk about in the music therapy room. But then her attention is suddenly caught by the familiar songs that I sing to her. She walks towards me and seems attentive and looks intensively at me. She then comes to sit down besides me for a while, sometimes falling asleep after a few songs.

Mrs F suffers from amnesia and has "lost" her memory. Does this then mean that she is not remembering anything at all? In order to answer this question, I shall focus on different memory systems.

First of all, memory can be divided into a short-term and a long-term memory function. Normally both are involved, when we are exposed to an external input and respond to this. And both functions are involved when we learn new things and recall episodes or facts.
Short-term memory is our working memory that is influencing attention and executive functioning and is related to cortical structures of the brain.

Long-term memory is not only an ability to remember things from long ago, but more specifically it is our ability to register information, to organize the information in a meaningful way, and our ability to recall the information when needed. This means that long-term memory has to do with encoding, storing and retrieving information (Zillmer & Spiers 2001, p. 160). Memory functions can not be separated, as they seem to overlap and influence each other. Still, it makes sense to separate the memory system in more subsystems.

Long-term memory is here separated in a declarative and a non-declarative system. Declarative memory is what is explicit and what we are conscious about, e.g. when we remember facts. People with a developed semantic memory are good to have on your team, when playing Trivial Pursuit.

Episodic memory is remembering personal experiences or episodes, e.g. your first travel to Paris or Jyväskylä, or other exotic places.
Declarative memory can be damaged by single lesions in the brain. This is not the case for non-declarative memory that refers to a variety of memory functions, e.g. the memory of routines, of biking, or playing "für Elise", or how we adjust our behaviour to implicit rules in an exclusive restaurant or in a church.

Short-term memory (or working-memory) is a component of long-term memory, but mainly involves cortical structures, especially prefrontal cortex. In long-term memory non-declarative memory (or procedural memory) involves various sub-cortical structures in the brain in a dynamic integrated system. The first signs of Alzheimer's disease are loss of episodic memory in a process where Hippocampus (a Limbic structure) is isolated from Cortex.

What I mainly want to stress with this, is the idea of multiple memory systems, e.g. presented by Joseph LeDoux in 1998.

In the case of Mrs F, the degeneration of her brain has damaged pre-frontal cortex and therefore especially short-term memory functioning. Additionally she seems to have lost semantic and episodic memory. When I in music therapy sing to her, it might be a way to activate procedural memory systems, priming less damaged sub-cortical structures that are components of our complex memory network. Memory and identity are strongly connected, and therefore memory functioning and alternative ways to facilitate memory are central to clinical music therapy. Not only neurodegeneration affects memory. What and when we memorize is dependent on attention.

Attention

When Mrs F approaches me in the music therapy sessions she seems to pay attention to me (the music therapist), to my sounds, or to the song. When you see Mrs F walking about at the unit, you see that she is attentive to door knobs. She will try every door knob she passes. But otherwise it is very difficult to catch her attention.

From research in mother and infant relationship Daniel Stern, in his book from 1977, writes that when a mother stimulates her baby too little, the child will lose interest and not pay attention to what she is doing. If the mother is stimulating the baby too much, he will turn away or start crying.

But "When the level of stimulation is more moderate, somewhere between the two extremes, his attention will be more easily captured and maintained" (Stern 1977).

In many brain dysfunctions we see symptoms of attention disorders, where the person is not able to focus attention, to divide attention (being able to do more things at a time), and to sustain attention.

What Stern tells us to do in order to catch and maintain attention is to stimulate, not too much and not too little, but at a moderate level. Although Stern is dealing with infant research, he describes basic human interaction that is also relevant to this population.
**Arousal**

In order to illustrate attention regulation I want to integrate theories of arousal. A person with attention deficits might have big difficulties in processing stimuli. If the television is turned on with loud sounds and flashing images this might be inputs that intensify the chaos that this person might feel. With too many inputs the person ends up in a hyper-aroused stage showing restlessness, vigorous gestures, speedy talk, and a fast heartbeat. A person in a low state of arousal, a hypo-aroused state, shows little activity, apathy, withdrawal, slow heartbeat, and little verbal and nonverbal communication.

At a balanced and moderate arousal level, in a situation with moderate stimuli, the person is most attentive to the environment and to own needs. At this balanced arousal level the person has most possibilities for optimal performance (An elaboration on performance and performance as health can be found in Aldridge's book from 1996).

As a result of neurodegeneration and of either hypo- or hyper-arousal a person might lack abilities of focussing and sustaining attention, memorizing, and controlling and timing movements and responses. Having these deficits causes problems in communicating and entering dialogue with other persons. Communication and interaction depends on synchrony and reciprocity, and from research done by Steven Malloch (1999) and Colvin Trevarthen (1999) we see that even infants time and adjust their responses in communication with their mother.

**Communication and dialogue**

Neurdegeneration might lead to primary symptoms showing a person who is no longer able to communicate. Not being able to communicate leads to secondary symptoms. In a paper from 2001 David Aldridge writes:

"When dialogue fails then we have alienation and despair ... Patients may be forced into a silence that they have no possibilities to neither transform nor structure, they are banished from the social to an isolated and degenerated self (Aldridge 2001)."

Facing these severe implications of communication breakdown, Aldridge goes further and calls neuro-degenerative diseases dialogic-degenerative diseases. The word dialogue stems from Greek and means words/thought/reason (logos) between (dia). This implies an understanding and exchange of `logos` `between` two individuals. Logo's counterpart is psyche, in Greek mythology the personification of the soul; of mind and spirit. In this sense dialogue is seen as an understanding and exchange between two individuals of both psyche and logos - of both reason and feelings. Seen from a dialectical or rational viewpoint emotions are illogical and does not belong to logos. Seen from modern neuropsychology (e.g. Damasio 1994) feelings are essential in human ability to judge and make decisions. When dialogue fails because of neurodegeneration we are not able to share reason and feelings, and it becomes difficult to meet our psychosocial needs.
**Psychosocial needs**

This leads me to a short introduction on psychosocial needs and on the work of the psychologist Tom Kitwood who has done important research in dementia care. Kitwood defines a need as "...that without which a human being cannot function, even minimally, as a person" (Kitwood 1997, p. 19). Instead of describing agitated and aggressive behaviour as problem behaviour, Kitwood describes these as attempts at communication that is related to need.

In order to describe the subjective world of dementia, Kitwood describes a cluster of five great psychosocial needs: comfort, attachment, inclusion, occupation, identity, which come together in a central need for love. When psychosocial needs are not met secondary symptoms of the degenerative disease might occur. Symptoms like: repetitive behaviour, catastrophic reactions and situationally inappropriate behaviour.

How is it possible to meet these basic psychosocial needs? Here Kitwood puts up 12 positive interactions that might function as strategies to meet psychosocial needs. I will not elaborate on these, but focus on three specific strategies: validation, holding, and facilitation that are described as distinctly psychotherapeutic techniques.

**Validation**

Kitwood describes validation as an attempt to understand a person's entire frame of reference, even if it is chaotic or filled with hallucinations (Kitwood 1997, p. 136). It is a way of acknowledging a person's feelings and responding to them. If an old woman with dementia tells me she wants to go home to her mother, a reality orientation approach would be to tell her that her mother has died many years ago and that she has to stay in the residential home. A validation technique would be to respond to her feelings of being unsafe and not feeling at home where she is.

**Holding**

Holding is a term that is also used in client-centred therapy, e.g. by Rogers (1951) and Winnicott (Davis & Wallbridge 1981). Kitwood describes holding as providing a safe psychological space, a container, where tension, vulnerability, and conflicts may be exposed.

**Facilitation**

Facilitation is important to all music therapy, as we as music therapists focus on creativity and resources, enabling a person to do what otherwise he or she would not be able to do (Kitwood 1997).
Building up the music therapy session

I have now given a broad introduction to themes on Neurodegeneration, Primary/secondary symptoms, Multiple memory systems, Attention and arousal, and Dialogue and psychosocial needs.

All themes are relevant to how the clinical music therapy setting is built up - when working with clients with a dialogic degenerative disease.

In the following I focus on 4 steps in the music therapy session with a client group suffering from severe dementia. An inclusion criterion for participants in the study (Ridder 2003) was among other criteria, that they would show symptoms of agitation; that they in periods of the day would show hyper-arousal. All six persons are residents at a geronto-psychiatric unit, referred to this place because daily care became too problematic at the local residential home.

1. Focus attention

I start every session by singing a special song. Especially in music therapy with children there is a tradition of using hello-songs. With participants having severe memory deficits it makes sense cuing the beginning of the session with a song in order to focus attention and compensate for missing short-term memory and in this way preparing the person to what is going to happen. A song, as well as contextual and social cues, activates memory traces in the brain, and speed up the retrieval process. Contextual cues organise the person in time and space. The person might at some level recognise the room, the songbooks, and the sofa we sit in. Social cues depend on our interaction; the way I, as the therapist, greet and welcome the person and what we do together.

Clients seldom recognise me, if we meet outside the music therapy room. But when we then enter the room and the person sees me, the songbooks, the furniture, and hears the hello-song it is very often clear that he or she recognizes me and has an understanding of what is going to happen.

Some clients need several sessions, depending on cortical functioning, before some idea of the music therapy is constituted. This means that the first many sessions might deal with establishing a structure by stability and cues.

2. Regulate arousal level

When it is possible to catch the attention of the client and facilitate some understanding of what is going to happen, the next step in the session comes to the foreground. Now it is relevant to regulate arousal level to a moderate level, where it might be possible to maintain attention. We have seen that there seems to be a relation between medium levels of arousal and environmental attention.
The structure of the music therapy might in itself have an indirectly regulating effect. Apart from this, the therapist can regulate arousal level by different techniques. Being aware of musical elements (timbre, tempo, volume, pitch, timing...) it is possible to either decrease or increase arousal.

It is possible to regulate arousal level making use of social elements. The therapist can make use of his or her own presence in order to regulate. Rhythm, proximity, attitude, and expectations might be used to either stimulate or calm down the client.

In the example with Mrs F the singing at some level has a calming effect on her. In order to assess arousal level I registered the number of times she verbalized one of the two words she has left.

In our 2nd session she used these words more than 500 times, but the number decreased dramatically. This is not information enough to tell if her arousal level generally decreased, and needs to be combined with other observations. Additionally I measured Mrs F's heart rate by daily measurements in the same time period as the music therapy. Heart rate was measured daily in 5-second intervals the week before a month with 20 music therapy sessions, and the week after. A statistical t-test showed a highly significant decrease in Mrs F's heart rate. In connection with more observations this points to a decreased arousal level after the music therapy, - even a whole week after the music therapy ended. In the study 5 of the 6 participants showed significant decreases in heart rate after music therapy.

3. Dialogue

Now, after having built up a recognizable structure using stability and cues, and having used arousal regulating techniques, we have the potential for dialogue and meeting of psychosocial needs. When dialogue fails and the person with a degenerative disease is isolated from social contact, it is here we have a possibility of breaking the isolation. The songs in this part are not used to form a structure, or to regulate, but mainly to meet the person. There seems to be certain songs that are strongly connected to life story, that represent a certain period of life, and where certain feelings are bound. If it is possible to find these personal songs there seems to be a key to memories that are still there, in spite of severe amnesia. The therapist shares the feelings that are represented in the songs with the client, in a way that is adjusted to the client's capacities.

4. Conclusion

Like a piece of music it has a stabilizing effect when the music therapy session is concluded in a stable form. Again the structure is built up by stability and cues and with the use of one or more songs that signalise closure and stability. When the session has a clear form, time is also given a form. This might give the client an understanding of continuance and stability.
Besides ending the session, the therapist must ensure that the client is guided to a new secure basis. The carry-over-effect of the music therapy is better maintained, if the therapist ensures that the client is not dropped into a new chaos, but led to basis, where he or she feels secure. This means close collaboration with staff that `takes over’ after the therapy.

**Summing up**

In order to compensate for memory and attention deficits different kinds of cuing gives stability, and constitutes the structure of the therapy. The songs function as cues compensating for specific memory deficits by involving other memory functions in a multiple memory system (see table 1.1)

The next step in the music therapy is to regulate arousal level to a balanced level, where the person shows most environmental attention. Musical elements and social elements are important in the regulation. A state with moderate arousal and environmental attention enables the therapist to enter dialogue with the client. By using psychotherapeutic techniques and songs with a personal meaning it might be possible to meet psychosocial needs. Concluding the session is part of the structure and ensures stability.

**TABLE 1. Four steps in the music therapy session**

<table>
<thead>
<tr>
<th>Level</th>
<th>Components</th>
<th>Aspects</th>
</tr>
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<tbody>
<tr>
<td>Focus attention</td>
<td>Structure: stability and cues. Songs as cues.</td>
<td>Constitutional</td>
</tr>
<tr>
<td>Regulate arousal level</td>
<td>Musical and social elements. Songs that stimulate/sedate</td>
<td>Regulative</td>
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<tr>
<td>(environmental attention)</td>
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<tr>
<td>Dialogue</td>
<td>Focus on psychosocial needs. Validation, holding, facilitation Songs with personal meaning</td>
<td>Dialogical</td>
</tr>
<tr>
<td>Conclusion</td>
<td>Structure: stability and cues. Songs as cues.</td>
<td>Integrative</td>
</tr>
</tbody>
</table>

**Mrs D**

At the European music therapy conference in Finland I had the opportunity to illustrate the different steps in the clinical setting by short video clips. I do not have that possibility here. Instead I will refer to the case of Mrs D where the arousal regulation was important in order to be able to enter dialogue.
Mrs D's diagnosis reads vascular dementia with frontal character and confusion of cerebellum. She has good verbal functioning, but never-the-less scores 5 out of 30 points on the Mini Mental State Examination (Folstein 1975), indicating severe dementia. According to the CMAI (Cohen-Mansfield's Agitation Inventory, Cohen-Mansfield 1996) she shows agitated behaviour several times a day for longer periods. She shows verbal aggressive agitated behaviour by shouting and scolding, and physically aggressive agitated behaviour when she hits staff or throws her dinner, china or other things on the floor. She is medically treated for both depression and psychosis. Mrs D has recently broken her hip bone and staff prefer her to remain in the wheelchair during music therapy. She hears very badly, but does not want to use hearing aids.

Before our 6th music therapy session Mrs D has been very upset most of the morning. Already when I enter the unit I hear Mrs D shouting. As usual before a session, I have a word with her contact staff, before preparing the last things for the session. I hear Mrs D shouting for coffee, and blaming staff that she is not allowed coffee when she wants. A staff member tells her that she has just drunk coffee, which makes her even angrier. Later, having prepared the music therapy room, I open the door to fetch Mrs D and she is already close to the music therapy room. A peer resident is pushing her wheelchair down the corridor. On the way the wheelchair has collided with a rollator, belonging to another resident sitting in an armchair. This resident is very angry, and so is Mrs D who wants the involuntary drive to stop, and shouts the best she can. Mrs D continues shouting in the music therapy room, but does not make any attempt to leave the room. Her comment when I start singing is: "Oh, belt up, #" and after the song she asks in a schoolmistress' voice: "Well, are you trying to learn singing?" As usual, I give her my hand and greet her during the first song. She takes my hand, and keeps holding it, which is in contrast to her verbal rejections. I start singing the next song, but do not look at her as I assume that would be too demanding. Suddenly in the refrain she joins in the song. She sings the words, but in a very angry manner. In the end of the song she corrects the text I am singing. I repeat the line like she wants it, and after a few more scornful comments she remains silent. After the 4th song Mrs D blinks and in the 6th song she closes her eyes for shorter periods. She does not fall a sleep, but often closes her eyes during the altogether 17 songs. I extend the session as I think she needs the rest after a turbulent morning. I sing songs that in the beginning are "neutral". I have the feeling that too "sooting" songs could be provocative to her, but gradually I introduce more "melancholic", slow, minor scale songs. When I sing the last song - a song that is used to conclude the sessions and that she likes very much - she moves her head slightly from side to side in beat. After the song she gives me a smile. I ask her if she wants to go out into the garden where she likes to be on warm summer days, and she answers in a very attentive and clear manner: "We can do that. The weather is nice today ... lovely ... it seems to be fine today".

In the beginning of this session it is not possible to enter dialogue with Mrs D. I here use the songs to keep the structure in order to indirectly regulate her arousal level. I am accepting her tension, but without matching or validating it. It is important to notice that Mrs D has damages in her frontal lobes and that she is not able to be her own `conductor'. When she is in this hyper-aroused state it adds to her anger, if I mirror or match the anger. After the first two minutes of the session Mrs D does not join in the singing or
verbalise anymore, and there is a clear decrease in her heart rate that is registered during the whole session.

The contextual and social cues make it clear to her what is going to happen and support her memory processing, and it is possible to regulate her arousal level by the songs. She calms down and later seems attentive and open for dialogue, and I sing familiar songs that I feel share her feelings of sadness or melancholy. In this way I use a validation technique acknowledging her emotions and responding to them.

After our 8th session, where Mrs D once again has been very upset in the morning, she is very relevant and clear at the end of the session in spite of severe dementia. She is able to put in words that the music therapy made a change to her. This is unique as none of the other participants in the study were able to communicate their thoughts verbally in this way. But although they were not able to talk, the music therapy shows that they were offering communicational cues to others and were capable of entering into dialogue when the music therapy sessions were built up in a way that compensate for their deficits. Mrs D concludes:

"It was good that you came today (laughs) ... I totally forgot why I was sad. But I was ... Never mind (laughs) ... Well ... which song are we going to sing tomorrow?"

Thanks to

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