

## **Abstract to Fourth International Meeting in Pediatric Neuromuscular Rehabilitation**

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### **Potentials in narrative approaches to rehabilitation**

In this presentation I will talk about how narratives work and how they can be used in order to bring out types of experiences, emotional truths and deep reflections that are usually not accessible by standard scientific methods. A narrative approach does not only mean a qualitative way of questioning but attempts to establish a particular type of mood where the person is encouraged to restore elements from memory that have been of vital importance in that person's life, memories that have some kind of deeper significance because they usually mark some turning points in life and are for this reason loaded with meaning. I will talk of the distinction between narratives, report and arguments, different types of turnings-points (slowly emerging vs unexpected, departure vs. collapse, loss of meaning vs. gaining new meaning) as well as the idea of rehabilitation as a biographical project and how individuals use biographical projects and narratives to colonize the future and continue their biographical narratives in spite of disappointments and life crises.

### **Talk**

What is a narrative and how can a narrative approach help us better to understand the problem of pediatric neuromuscular rehabilitation?

A narrative is basically an attempt to retrieve subjectively felt experiences at a previous time of our lives, to reflect upon these experiences, to establish subjective meaning and to communicate what we have believed what we have learned.

Narratives can also be analyzed in a scientific manner and compared with each other to discover hidden patterns and to test emerging or previous hypotheses, but the prime function of the narrative is to retrieve subjectively felt experience and establish some kind of meaning that can be communicated from person to person

Here is a possible list of what such narratives are about:

- Personal Memories
- Significant Others
- Turning Points
- Strong Emotions
- Meaning
- Reflection
- Communication
- Report
- Self-presentation
- Argumentation

- Legitimation

For a narrative to be valid in the sense of authentic we should try to stick as close as possible to the “upper” part of the list. A narrative becomes more authentic the more it stays close to the subjectively felt experience at the time it was made by the narrator. The more the focus is on the “lower” part, that is the more the narrator feels the need to legitimate what he/she did at a previous time of life, the more it becomes less a retrieval of subjectively felt experiences of the time in which these experiences were made, and the more it becomes an attempt to defend the self in the present situation.

A major point of narratives is thus to avoid what we could call the “Freudian” mechanism of self-defence.

Self-defence is also a kind of communication but it is a communication that does not open itself up, it hides more than it reveals, it represses actually felt experiences.

I have now said something more general about what the function of narratives are. I will now look more into how narratives work. There are two important distinctions here that should be made. These

- Plot and story
- Telling and showing

Plot is the order in which a narrative is presented. The story is the actual order in which the story was experienced. These two rarely coincide, but are important for the way a narrative establishes meaning. A detective story like *The Da Vinci Code*, uses this distinction in a very clever and highly professional way but each narrative used by a layman in principle uses the same distinction in order to establish meaning.

In a research interview, the plot is usually laid out by the researcher who has selected some “themes” usually theoretically derived, these theoretically derived questions are then transformed into a more concrete questions that the informant is supposed to answer.

Somewhere within this plot, the highly subjective story of the narrator, which does not necessarily follow the rules of scientific analyses, have to be squeezed.

One way to avoid this and to get the lived story of the narrator going, is to abstain from a theoretically structured interview and to let the narrator self decide what is important or not to talk about.

One way of doing that could be to follow a plot which is chronological, that is structured according to the time dimension. This does not mean that we have to start with the past and slowly move to the present. We can start in the present and from there move back to the past and slowly work ourselves to the present.

Or we can focus upon a particular memorable event, some kind of turning point and make what novelists call flash backs, that is follow that memorable event as it unfolds and retrieve personal memories from the past as these earlier memories come about as a result of free association.

A turning point is some kind of dramatic event in life, which leads to some kind of reorientation and change of meaning. We tend to see things in a different manner from before. These turning points are very good to focus on, in order to retrieve personal memories that are somehow related to that event, that turning point in life.

Some turning points can come as a total surprise, a bolt from the sky, others have been slowly growing from a long time. The point is that the turning-points are good to retrieve the lived experience, the story, they are good plots for such narratives.

### **What about telling and showing?**

Telling is a more distanced and indirect way of telling a story. Showing is more concrete and makes the story come better alive. It creates a stronger feeling of presence.

“Dialogue” is a typical method of “showing” it makes the scene come alive for us. Peter said .... And then I said.. etc.

Close description of the situation in which the event took place, is another way of “showing.” Hemingway’s short stories and novels are exemplary of this way of narrating. Hemingway’s writing almost exclusively consists of close and very concrete descriptions that have the function of establishing a mood, followed by a dialogue, which helps us establish who the characters are.

Here are some examples from his novel *A Farewell to Arms*  
It begins like this:

In the late summer of that year we lived in a house in a village that looked across the river and the plain to the mountains. In the bed of the river there were pebbles and boulders, dry and white in the sun, and the water was clear and swiftly moving and blue in the channels. Troops went by the house and down the road and the dust they raised powdered the leaves of the trees. The trunks of the trees too were dusty and the leaves felt early that year and we saw the troops march along the road and the dust rising and leave, stirred by the breeze, falling and the soldiers marching and afterwards the road bare and white except for the leaves.

Such descriptions establish a mood. It helps us make the situation in which the story unfolds come alive, not only for the listener, but for the narrator him/herself. It establishes a strong feeling of presence, and hence makes it easier to remember what actually happened.

I have a German colleague who lives in Berlin and wanted to interview East- and West Berliners who lived in one part of the city but worked at the other part at the time the Wall that came to divide the city for almost 30 years was built in 1961. She wanted to know exactly how they, she called the, “Grenzgänger” experienced this turning point in their lives.

What she did in order to establish a good mood for narration was to look at old fashion magazines and how people were dressed at the time, but also what music was played in the radio etc. and when the narrators came for the meeting, my German colleague, met them dressed in one of those fancy costumes and hats at the time, playing some record from the time she had heard etc. in order to establish them good from them. All in order to retrieve their personal memories from the time,

The other technique Hemingway uses to go from mere telling to “showing” is use of dialogue. Here is an example.

The lieutenant, Rinaldi, lay asleep on the other bed. He woke when he heard me in the room and set up.

“Ciao” he said. “What kind of time did you have.?”

“Magnificent.”

We shook hands and he put his arm around my neck and kissed me.

“Ough,” I said.”

“You’re dirty” he said. “You ought to wash. Where did you go and what did you do? Tell me everything at once.”

“I went everywhere. Milan, Florence, Rome, Naples, Villa San Giovanni, Messina, Taormina ...”

“You talk like a time-table. Did you have any beautiful adventures.”

“Yes.”

“Where?”

“Milano, Firenze, Roma, Napoli ...”

“That’s enough. Tell me what was the best.”

“In Milano. “

“That was because it was the first. Where did you meet here? In the Cova? Where did you go? How did you feel? Tell me everything. Did you stay all night?”

In a biographical interview, this type of relaxed but questioning dialogue is the one we as researchers should strive for. As Rinaldi, we should go on asking for specific details. A narrative should not be a mere report, an assemblage of meaningless information. Who wants to know what cities a person has visited? Such neutral reporting makes one sound as a time-table. The art of telling is telling something interesting, something meaningful, something with the potential of being a transformative experience. Like for instance some persons one met and that met something import for you.

In interviews I have made with visual artists in Northern Jutland one of the artists talks of a particular eye-opening or transformative experience. He was brought up in a working class home, there were no paintings and few cultural artificats in his home. When he was about 16 he happened to visit a museum of modern art, and was stunned by what he saw. He had never before thought of becoming a painter, his father had other plans for him that were closer to the fathers occupational experience and social background But this particular meeting, this encounter with a totally different world, changed this individual completely, he became a different person.

Providing these details in the dialogical form, made is easier to see that we were here dealing with a true turning point.

In this case it was an unexpected type of turning point, a bolt from the sky.

Later in the narrative, the artist talks about what happened to him five-six years later. He had now been working with other visual artists, he had a network and the start of a new professional identity, but he was still somewhat hesitant about committing himself 100 percent to a career as artist. He talked with people he knew about his dilemma and one of them, adviced him to take an education as librarian or teacher. In this way you will still have plenty of time to produce art, but at the same time make sure that you have a livelihood. Which this artist did. He took an education as liberarian and continied doing art in his free time.

Here clearly we have a turning point again, a transformative event but this time the element of surprise is much less present. We are talking of a more slowly emerging decision. It was a very important decision in his life, it clearly influenced it many years to come. At the time of the interview the artist was 55 years old and still worked as a librarian and did art in his spare time, something he was not too happy about, but he could see no other alternative, because he was now married and had children to support. The interview thus became an opportunity to reflect upon that previous important event in his life. Since the event came 5-6 years after the eye-opening event, it on the other hand was not an unprepared decision. It must have matured over a long time. The advice from the friend to take an education as librarian, was thus less decisive, it merely tipped the scales of a decision that had been growing for quite a while.

Rose Ebaugh, an American professor of sociology, who was originally a catholic nun before she left the cloister, in a book she calls "becoming an Ex." found that such turning points that have been prepared for a long time, usually takes one of the following forms;

The last straw or the drop that makes the glass overflow. The person had been in doubt for a long time about say a marriage, is he or she the right partner for me, had been searching for alternative partners, then came an event that was interpreted as the last straw, "he was rude to me" etc. and said, "now I want a divorce."

The sudden opportunity. Ebaugh had been thinking of leaving the cloister for some time. There is a six-year promise rule which allows nuns to regret and renew the promise after six years and she used this opportunity to liberate herself from the promise to remain a nun

Saving face. These are excuses, made by the person in order not to have to face an awkward situation. . For instance if you are unhappy about a job and you know that your boss wants to get rid of you and your doctor suddenly tells you that you can no longer do that job out of health reasons, you gladly grab that excuse and in this way you are able to save face and get yourself out of an awkward situation.

My stepfather who is 85 years old and my mother have a huge garden in Sweden. For years my stepfather's old friends kept coming after him asking him why he didn't sell the house and the garden and move into an apartment in the city like everything else. After years of quarreling about the issue, my stepfather finally persuaded my mother to give up the garden, a decision she immediately regretted and was very unhappy about it. Then my stepfather had his yearly exam by the physician and when my stepfather told him about his decision to sell the house and garden and move to the big city, the physician looked at him and said. "Why are you doing this to yourself. Do you realize what a job it is to move from a house where one has lived for forty years as you have. It might very well kill you. No, if I were you I would forget it. Which my stepfather immediately did and he and my mother have not talked about the issue since. He finally found the excuse he could tell to his old friends. He really did not want to move, but felt pressure from outside to do it, and now he could save face and still do what he wanted to do.

Finally Ebaugh talks of what she calls "either- or" situations. These are situations where you are faced with a decision of life and death. Your doctor for instance tells you, you must stop smoking immediately or it will kill you or you must start doing exercise or your health will deteriorate very rapidly or you must undergo this dangerous operation because the alternative is much worse.

All sitting in this room probably recognize these type of either- or situations, which might or might not be effective if you want people to make an important decision in your life that

are inconvenient for the person, resisted or postponed but has to be done and often has to be done now. The decision probably should have been made long before, but maybe the serious problem was not detected until now or the patient has been procrastinating and now is the time to make that decision or it could be too late.

Often a desired and recommended change of life style or a cure or something similar has to last in order to be effective. This is a big problem in a rehabilitation perspective. How do we accomplish this long-term continuity? In the literature on narratives, this is called Commitment. The concept has been introduced by another American sociologist called Howard Becker. For Becker a commitment is a long-term identification with a given task, role etc.

The reason we stay committed, according to Becker are three:

- Because we have already invested so much in the task or role and giving up now would mean a big waste
- Because we might lose economically
- Because we might feel ashamed of giving up too easily

The Norwegian philosopher John Elster has expanded upon the last aspect, about how we cope with shame and had presented the following model to strengthen a commitment

- Private sidebet. Here you promise yourself to keep the promise you made
- Public sidebet Here you make a promise in the presence of others and feel
- more ashamed if you walk away from your promise
- Manipulation of physical set. You seek out environments that are good for what you have promised to do and avoid environments that are bad
- Manipulation of psychological set. You engage in more general characterbuilding such as taking cold showers in the morning etc.

Anthony Giddens, the English sociologist, has summarized much of the thinking on narratives. He suggests that such narratives are actually ways in which we establish our self-identity. A narrative talks about the past, it happens in the present, but it is actually about the future.

It was the English novelist George Orwell who said that whoever controls the past, controls the future.

Anthony Giddens has used this brilliant idea and transformed into a contemporary diagnoses of what he calls late modernity.

In late modernity, we try to control our future by controlling the past, that is by continuously telling stories about our selves.

Giddens calls this to “colonize the future.”

The way we colonize the future, is by engaging in ongoing self-narratives.

What is important is that these self-narratives can change over time. Let me end by returning to the artist who became a librarian.

We had two meetings. At the first meeting, he told me that he was actually very content with his previous choice 35 years ago, to become a librarian and to live for rather the off art. This allowed him to be more authentic in his art. Because he didn't have to worry about selling his art, he could be more authentic in his choice of artistic expression.

At our second meeting he told me a slightly different story. Now he told me and colleague that was also present, that he had actually accomplished what he had set out to accomplish 35-years ago. He had become a recognized artist in Denmark. To become an internationally recognized artist had never been his goal. Therefore he had never applied for a scholarship abroad. Moreover he had his family and children to think of.

At a third interview we made, not with the artist himself but with an art collector, a previous, now retired school psychologist, the latter told us that the same artist and he had been talking for half a year, where the librarian-artist presented his dilemma. His big dream was to quit his job and become a full-time artist. He had reached a certain point in his life where this was the necessary step, but was ambivalent about it.

There are two points about this story which related to the theme of my paper. One is that biographical narratives are ongoing projects, they change over time. The ways they change and why they change, can best be studied by looking at biographical narratives people make about themselves, that is how they control the past in order to control the future.

Another point is that such biographical narratives are not always authentic at the start. There is a Freudian mechanism of self-defence going on which at the beginning make these narratives look more like self-presentation or self-legitimation than true reflections about inner thoughts and experiences. Hence it is extremely important that we are patient in our dealing with patients or other clients who are engaged in colonizing the future. We might not get the authentic story at the start. We need to go on. For this we need to establish the right mood, by being aware of the difference between plot and story and about telling and showing.