Journalistic Narratives as Complementary User Involvement in Multidisciplinary ALS Rehabilitation

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Background
User involvement is essential to the idea of rehabilitation. It is needed to develop methods that communicate subjective experience as a constitutive force and integrated part of the individual rehabilitation process.

Purpose
To investigate whether journalistically mediated personal narratives authorize the ALS patient within the multidisciplinary rehabilitation by voicing views complementary to professional’s perceptions.

Methods
Six patients with ALS have been selected in collaboration with the national rehabilitation centre for neuromuscular diseases. Each is interviewed and portrayed in journalistic stories four times through one year. Concurrently, the stories are distributed to the patient’s significant rehabilitation professionals, and finally published as one continuous narrative on the website of the national rehabilitation centre (Table 1).

Table 1. Participants’ age, sex, time of diagnosis and inclusion, marital status and children/grandchildren, former occupation, and disease progression.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Sex</th>
<th>Time of diagnosis</th>
<th>Time of inclusion</th>
<th>Married</th>
<th>Children under age Grandchildren</th>
<th>Occupation prior to diagnosis</th>
<th>Speech at inclusion Per November 2010</th>
<th>Respirator at inclusion Per November 2010</th>
<th>PEG-tube inclusion Per November 2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>51</td>
<td>M</td>
<td>01/2009</td>
<td>01/2010</td>
<td>Yes</td>
<td>No</td>
<td>Bank clerk</td>
<td>Affected</td>
<td>No BiPAP</td>
<td>No</td>
</tr>
<tr>
<td>II</td>
<td>53</td>
<td>M</td>
<td>02/2009</td>
<td>02/2010</td>
<td>Yes</td>
<td>Yes</td>
<td>Gardener</td>
<td>Affected</td>
<td>No BiPAP</td>
<td>No</td>
</tr>
<tr>
<td>III</td>
<td>63</td>
<td>M</td>
<td>03/2010</td>
<td>03/2010</td>
<td>Yes</td>
<td>Yes</td>
<td>Service technician</td>
<td>Affected</td>
<td>No BiPAP</td>
<td>No</td>
</tr>
<tr>
<td>IV</td>
<td>58</td>
<td>F</td>
<td>04/2010</td>
<td>04/2010</td>
<td>Yes</td>
<td>Yes</td>
<td>Dental technician</td>
<td>Unintelligible</td>
<td>BiPAP Tracheostomy</td>
<td>No</td>
</tr>
<tr>
<td>V</td>
<td>37</td>
<td>F</td>
<td>05/2007</td>
<td>05/2007</td>
<td>Yes</td>
<td>Yes</td>
<td>Factory worker</td>
<td>Affected</td>
<td>BiPAP Tracheostomy</td>
<td>No</td>
</tr>
<tr>
<td>VI</td>
<td>63</td>
<td>M</td>
<td>07/2010</td>
<td>07/2010</td>
<td>Yes</td>
<td>Yes</td>
<td>Dairy engineer</td>
<td>Unintelligible</td>
<td>Tracheostomy</td>
<td>No</td>
</tr>
</tbody>
</table>

Table 2. Stories’ titles, main themes, and complementary subjective view.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Participant I</th>
<th>Participant II</th>
<th>Participant III</th>
<th>Participant IV</th>
<th>Participant V</th>
<th>Participant VI</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. and titles of stories produced per November 2010</td>
<td>I. Worse than the diagnosis II. Not only the end of the world III. You are allowed to hope</td>
<td>I. I couldn’t bear to lose II. We won in parenthesis III. I’ve never tried it before</td>
<td>I. The one I once was II. You should be like you used to be III. You don’t accept you live with it</td>
<td>I. It’s tough on the healthy one II. Deep down they don’t know how I put up with it</td>
<td>I. Look what I’ve written II. I’ve always been one who dare not say a word</td>
<td></td>
</tr>
<tr>
<td>Main themes of stories</td>
<td>Stemcell therapy, Children’s reactions, Emotional lability</td>
<td>Bodily losses, Suicidal thoughts, Dislike of professional personal care</td>
<td>Loss of speech, Loss of social life</td>
<td>Caregiver burden, Managing personal helpers</td>
<td>Fear and anger with the professionals’ prognosis, Loss of fellow workers and friends</td>
<td></td>
</tr>
<tr>
<td>Stories’ complementary subjective view</td>
<td>How to become an empowering memory to my children</td>
<td>How to balance between disgrace and self esteem, while reconciling with ALS</td>
<td>How to forgive faithless fellow human beings</td>
<td>How to console my closest relatives who suffer more than I</td>
<td>How to live in the moment, aware of the dangers lurking ahead</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>How to heal myself by staying true to my convictions</td>
<td></td>
</tr>
</tbody>
</table>

Results

Figure 1. Intimate Narrative Journalism. Quotes from I don’t need to be explained all the time (Participant VI).

Scene
Here lives a person, who does not like to be typecast. She says it and she shows it. Hanging from her living-room wall is a shiny sword, one meter long and pointing down, not the kind of knick-knack you usually find in the home of a 37-year-old woman. The CD case is just as unusual: a floor-to-ceiling Indonesian figure carved out of dark wood with a digital swinging from the back of his head.

On top of the bookshelves, a combat aircraft, masterfully put together from different types of solid wood. It is usually accompanied by another plane but that one has been damaged; she tells me. Her father brought it home to Jutland last time he was here to fix the defect.

It is Wednesday, July 14, 2010, and we are in K, a suburban town on the southern outskirts of Copenhagen. A is sitting in his wheelchair dressed in beige shorts and a flashing green t-shirt. Short dark hair grows over his eyes and a not so dominating smile is wide open in the midday heat. In the garden, a personal assistant is sunbathing while we are inside making a tentative effort to talk about A’s life with ALS and especially about why she does not really feel like talking about it.

Dialogue

“I sometimes feel over-informed. Then someone tells me that I’m trying to myself. Not! I know what the consequences are. But I don’t need to be confronted with them all the time. So I have thought a lot about this conversation and whether I really felt like having it...

“I, we have negotiated back and forth for some time. And that’s really interesting for me...

“...yes, but why?”

“Because that’s another way of having ALS. It’s just as right or wrong as all other ways. I bet there are other people like you...

“...who don’t want to relate to the problem. That is another example from the Institution for the Respiratory Disabled, where they found it very important to talk about it all the time. They really wanted me to understand just how serious this problem was. And to relate to it. But I can’t be bothered to. It’s not like I’m stupid. I know what the consequences are. I don’t need to be explained all the time. And again: I fully respect the experience professional people have and I know I’m not smarter than them. But I am and will always be the smallest one when it comes to my own body. Only I know what I feel!”

Symbolic detail

Two photos of A’s parents are displayed on a chest of drawers. To the left in black and white, is their wedding picture, to the right, in color, their 25th anniversary picture. On the wall above, a painting from the west coast of Jutland painted by an acquaintance who lived near the family’s summer cottage in B.

“The mailman’s daughter,” she giggles. As a child and young girl, people called her that because unlike her mother, father and little brother, she was very bland. “But I really was a mailperson’s daughter. My mother was a mailwoman!” A’s mother is not alive anymore; she died 53 years old from cancer of the liver a year before A became sick.

I want to know how she thinks her father handles his daughter’s disease. The question is painful, I realize, seeing A tear on her eye. “It’s very difficult for him to relate to,” she says. “And that makes you sad?”

“Yes.”

“Do you know anything about astrology? It’s said that if you have many planets in the Libra, you’re able to see everything from two sides. My problem is that I see everything from two sides. Sometimes it’s a pain in the neck.

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Table of Contents