

2 Between the Worlds of the Disabled and the Healthy: A Narrative Analysis of Autobiographical Conversations

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1. Theoretical-Methodological Background

The aim of the research is to gain understanding of the experience of the parents of physically disabled children. Special attention is given to the position of the parents in the border area between the two worlds: those of the disabled and the healthy. The theoretical and methodological tool enabling us to reach the goal is the hermeneutic and narrative approach (Čermák, 1999, 2002). Here we assume that story telling reflects the way in which our experience is structured and our understanding of the world and ourselves within it is constructed. If we as researchers want to learn something about the experience of being a parent of a physically disabled child, we may focus on the way such experience is structured through narration. The analysis of a life story allows for grasping the way in which disabled children's parents experience their fate, how they cope with it and what they make of it.

2. Research Participants and Data Collection Procedure

Participants

The sample of participants included ten parents of physically disabled children. The parents were clients of the Special Education Centre (SPC – “Speciálně pedagogické centrum”) attached to the Jedlička Institute for the Disabled. They comprised nine mothers and one father, which roughly corresponds to the proportion of males and females in the SPC clientele. Over a period of approximately one year Dušana Chrzová approached the parents with whom she worked as a special pedagogue at the SPC (this mainly involves integration of children with special needs into the standard education system) and those willing to communicate joined the research as participants.

Data Collection Procedure

A method of “narrative interview” was used (Schütze, 1999). The method is based on the above mentioned assumption that experience is naturally organized in stories. Therefore, if we stimulate the research participants to talk, we will obtain their experience in its natural form. The structured quality in this instance – rather than from the questioner’s activity – follows from the narrative form itself (Hendl, 1977). The “life-line” method was used to initiate and facilitate the narrative interview (Tyl, 1985). The participant was asked – without any further specification – to draw the line of her life. Next they were asked to mark a point on the line where they find themselves at present, and then to also mark important events of their lives. After that they were asked to tell their life stories in greater detail. The interviews were recorded using a dictaphone with the participants’ permission.

3. The General Procedure of Analysis and Interpretation

We processed the collected data in three phases that we called “readings” for this purpose. The phases – each of which comprised multiple readings of the transcribed conversations – may be briefly characterized in the following way:

- *the first reading*: emergence of the relevant narrative analysis categories from the data collected;
- *the second reading*: analysis and interpretation of conversations through the categories applied;
- *the third reading*: an attempt to capture the experience of the individual parents in its completeness.

4. The First Reading – Reading through the collected data over and over again to the emergence of the relevant narrative analysis categories

The analysis categories making it possible to understand the experience of the disabled children’s parents, should emerge from the text, ie. the collected stories. Therefore we at first tried to look for the common themes and only specify the more general categories and concepts based on the identification of the common themes.

4.1 Identification of a “General Script” and Recurrent Themes

The first area to emerge from the transcripts as eligible for generalisation was given a working name “general script”. What we had tried to identify was a kind of regular pattern as to development and sequence of phases of the related experience. We were able to extract from the narration of the parents a typical development, certain succession comprising the following phases: Most of the parents talked about a turning point in their lives, when they were more or less unexpectedly faced with the finding that their child was disabled. This was usually followed by the phase of making a diagnosis and looking for causes. The next phase concentrated on the solution of the situation, which mainly includes doing exercises with the child and achieving some success or failure to achieve improvement. The following phase takes place in the present, ie. at the time of my meeting the parent within the period of school attendance and coping with it. Most parents also talked about the future, ie. their prospects, plans and goals.

After we identified some regularity with regard to the development of parental experience phases, we proceeded to try and identify the recurrent themes (in this case more or less across the course of time). This step resulted in the following list of recurrent themes:

- causes, diagnoses, information;
- development of handicap, possibilities of change, exercises;
- school, coping and failing, teachers, assistants;
- conditions, finance, institutions, legislation;
- who is responsible for what;
- family members, friends, self-help communities;
- comparison of the healthy and the disabled worlds;
- time for the child and time for oneself;
- care for the child versus fulfilment in a career;
- satisfaction with life and self-fulfilment (self-actualisation);
- potentials, activities and emancipation of the child;
- child integration into the society;
- strategies of coping with the handicap;
- acceptance of fate;
- gains resulting from and the meaning of the handicap;
- prospects, goals, fears and hopes.

4.2 Attempt at Generalisation – Basic Concepts

The above list of themes became a basis for further generalisation. At this point we asked ourselves a question: what angles of view (concepts) could be applied to define the recurrent themes? We thought about the problem in the following way: Along with the physical handicap a “trouble” entered the lives of the parents. They relate to the “trouble” in different ways, they find themselves within a certain tension created between the “trouble” and the condition they perceive as desirable. They do something to deal with the “trouble” and the “trouble” does something to them. Also, they are not the only ones faced with the “trouble”.

“Trouble” is one of the crucial concepts of the narrative psychology, a central element that the narrative construction is derived from, rendering our experience (Bruner, 1986, 1996). Parents of the handicapped children are faced with a “trouble”, take a stand on the “trouble”, in other words, they take up a certain position: in relation to the child, their handicap as well the others.

In this context, two categories naturally present themselves that are part of the set of concepts used by narrative psychology. They include the category of *agency*, and the category of *positioning*. In relation to Bamberg (1997, 2004) we understand agency as a capacity to act with regard to circumstances, abilities or commitments. It is a way and a measure to which the agent is able to achieve the desirable or avoid the undesired (Chrz, 2004). This category allows for defining “who-does-what-to-whom” or “what-does-what-to-whom”.

Through the positioning category it is possible to describe the way in which the positioning of self, the others or circumstances takes place through narration. Positioning is also a way in which an individual accepts or gives responsibility. In loose connection with Bamberg (2004) three levels of positioning can be differentiated. The first level involves the way in which the narrator positions him/herself or others in the space and time of narration. This level of positioning relates to “what” is narrated. The second level involves the way in which the narrator defines their positions in relation to “whom” it is narrated, whether the person is present physically or just “implicitly”. Here the communicative or conversational context of the act of narration is in focus, which means that we “do something” to the others through the narration. The third level of positioning includes the broader social, cultural or historical context. As narrators we always find ourselves in the space of certain “normative discourses” and these to some extent predetermine the positions within which we can position ourselves (Chrz, 2004).

The three levels may be understood as three aspects of the same act of positioning. The way in which an individual positions themselves and the others within narration reflects both the position they take toward the recipient of their message, and the space of potential positions within a broader social and cultural context.

5. “The Second Reading” – Analysis and Interpretation of Conversations With Regard to the Concepts of Agency and Positioning

During this phase we proceeded from the general terms toward specific data, ie. we tried to “read” the texts of conversations in terms of the above described categories. This research phase led, among other things, to the specification of the initial temporary list of themes and their categorisation into several thematic groups.

5.1 Specification of Themes and Categories – From the Basic Terms to the Conceptual Outline of the Study

In terms of Agency Category (“who–does–what–to–whom”, “what–causes–what–to–whom”) we asked the following questions over the conversation transcripts (from the parents’ perspective):

- 1) What does the fact that I have a disabled child to my life, and what do I do about it?
- 2) How does the disabled child impact the others and how do the others impact the disabled child?
- 3) What does the handicap do to the child and how does the child respond to the handicap?

In terms of Positioning Category there were primarily the following two areas of questions considered:

- 1) How is responsibility divided between the parents, the child and “the others” (whether they include family members, friends, self-help communities or institutions)?
- 2) In what way are positions laid out within the movement between the “trouble” (disability) and remedy/solution (desired condition).

We have specified a number of themes and categories in relation to these questions. The categories represent a thematic outline of the analysis.

- 1) Between two worlds: the physically disabled and the healthy
- 2) With and without the child: deny oneself – live one’s own life
- 3) Responsibility: myself – child – others – responsibility
- 4) Strategy of coping
- 5) Explanation, evaluation, and justification

- 6) Life philosophy, creed
- 7) Plans, goals, prospects

Within this paper we will focus on the problems relating to the first theme describing the ways in which the parents' narration presents the position between the world of the disabled and that of the healthy, and the movement between the two "worlds".

5.2 Between the Worlds of the Handicapped and the Healthy

In their stories, parents lay out the positions between the worlds of the disabled and the healthy, in more than one sense. The two worlds create a certain "span" between the "trouble" and the desired condition, ie. the "span" within which parents as well as the other involved exert their efforts. The two worlds also, to some extent, correspond with two different "times", ie. the time parents spend with the child, ie. the time of "self-denial", and the time spent "without them", ie. the time in which parents live their "own lives". Also it is between the two worlds where emancipation of the child and their integration into society takes place. On the way between the two worlds there are goals, concerns as well as hopes of parents relating to the fate of their children. They are the worlds where parents and children, to different degrees, belong, and they may be both the source of security as well as threat. And finally they are the worlds of shared experience, having their value and normative dimension.

In relation to the two worlds two tendencies can be identified:

- 1) **CENTRIFUGAL** – a tendency to move away from the world of the disabled toward that of the healthy.
- 2) **CENTRIPETAL** – a tendency to move away from the healthy world toward that of the disabled.

These involve approaches taken by parents when they construct, through narration, positions and ways of agency, of themselves as well as their children and "the others". Typically both the tendencies are found – manifested in different ways and to different degrees – in the same parents.

Ad 1) We have recognized the first tendency, ie. **move from the disabled to the healthy world**, manifested in two ways. The first one is characterised by dissociating oneself (drawing a distinction between oneself ...) and the child from those in a worse situation (eg. from parents of non-walking children etc.). This tendency can be illustrated by the following extract from a conversation.

"We had a row with one other mum then and I say, just don't think you're so important, okay, you're just sitting here, making sweaters and showing how

unhappy you are, want everybody to see that, how sick your child is. I say, my kid is not so sick as yours, but I get up with him at four every day, do puzzles with him, we build with blocks, I do everything with him like crazy, run after him all day ...”

The other way of showing the mentioned centrifugal tendency consists in defining a child’s position as developing towards emancipation from the family and integration into society (ie. in terms of going to school and doing well, or later assert oneself in society). This can be illustrated by the following two examples.

“You don’t want to be a child, do you, being told by us what to do all the time...”

“I trust I won’t be lumbered with him for good, he’ll finally end up working with computers.”

Ad 2) We have also recognised the centripetal tendency, ie. **move away from the healthy world toward the disabled**, in two different manifestations. The first consists in identifying with the disabled as the community where values and relationships are found in contrast with the healthy world. This is shown by the following examples.

“I am glad it happened after all, as I got somewhere completely different, completely different, my values have changed completely.”

“And I am happy to have him in my life, otherwise I would not have met so many people, and it’s different now. I think about myself I would probably be more of a bitch, one would be a worse person, would be different.”

“I’ve seen people ... they were very ill – and had good friends around them, and in contrast, great big men – and all depressed, strong muscles and fitness is not everything.”

The other attitude (we may say more wide-spread) manifesting the mentioned centripetal movement consists in the. The tendency is illustrated by the following examples. tendency to move closer to the disabled community as the sphere of security and shared experience. The tendency is illustrated by the following examples.

“Not that we would have to, but we want to spend holidays with the handicapped, a disabled kid sticks out among the healthy, has to adapt him/herself, I feel more vulnerable among the healthy, it makes me feel sorry seeing the others are all right.”

“I would drop in on a friend with a disabled child, not a healthy one, we have the same problems, while with the healthy ones I would fear I might be a nuisance.”

The short pieces of interview show that while in the first instance the tendency to withdraw is motivated more by the consideration for the child, in the other it has to do more with the parent and their feelings.

6. Perspective of the Third Reading

The two above discussed readings of the interview transcripts may be followed by yet another reading, the third. The aim of this research phase is to grasp the configuration of experience of the individual parents. Unlike the second reading which focuses on the individual categories such as agency or positioning, here rather an overall level of description should be reached. What within the previous analysis had been artificially “taken to pieces”, should from the perspective of the third reading be reintegrated, ie. reconstructed with regard to the life story with its characters, plots and genres.

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