

Challenged life:

How to live and cope with slow physical decline

Herausforderndes Leben:

Wie man mit langsamem, körperlichem Abbau lebt und umgeht

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Abstract

For this research project, a retrospective interview with a 32-year-old woman who had been living with a diagnosis of multiple sclerosis for more than 10 years was conducted and analyzed. Over the course of time, the inner attitude of the research participant towards her disorder was shown to have been altered. Right after getting the diagnosis, her behavior was shaped by her having strictly rejected the fact that she had MS. Starting about three years ago, she manifested a gradual change in favor of accepting her body abnormalities. But this stance was not a matter of either-or logic: We found evidence of the coexistence of contradictions. This curiosity about simultaneously existing contradictions provides a means of negotiating the maintenance of self-consistency under the threat of deteriorating health.

Keywords

long-term-acceptance; chronic disease; MS multiple sclerosis; change of inner attitude

Kurzzusammenfassung

In dieser Forschungsarbeit wurde ein Interview mit einer 32-jährigen Frau durchgeführt und analysiert, die bereits mehr als zehn Jahre mit der Diagnose Multiple Sklerose lebt. Im Laufe der Jahre hat sich die innere Einstellung der Forschungsteilnehmerin gegenüber ihrer Krankheit geändert. Kurz nach Diagnosestellung lehnte sie es strikt ab, ihre Krankheit zu akzeptieren. Doch seit etwa drei Jahren hat eine schrittweise Veränderung begonnen, ihre körperlichen Erscheinungen zu

akzeptieren. Die beiden Standpunkte sind jedoch nicht gegenseitig exklusiv – die Evidenz deutet auf ein gleichzeitiges Vorhandensein zweier Gegensätze hin. Diese Forschungsneugier für gleichzeitig vorhandene Gegensätze war bei der vorliegenden Arbeit auf den Umgang mit der eigenen Selbst-Kontinuität bei drohender Gesundheitsverschlechterung gerichtet.

Schlüsselwörter

Langzeitakzeptanz; chronische Erkrankung; MS multiple Sklerose; Veränderung der inneren Einstellung

In writing this paper, I made an effort to understand how a person with a given diagnosis of impending long-term health decline deals with slow physical deterioration. My understanding is based on a research interview with Hanna¹, a 32-year-old woman with a diagnosis of multiple sclerosis.

1 *Medical background*

To provide a framework for understanding the deep feelings and psychological effects the subject presented in this case, I have included a brief summary of the disease in question, *multiple sclerosis* (MS). MS is a condition that mainly affects the messaging function of the central nervous system (i.e., the brain and spinal cord), and whose presence fluctuates over time. So-called inflammations lead to an impairment of the messaging role of the nerves, and can culminate in occasional relapses. These relapses are signified by major symptoms involving short-term disabilities, such as not being able to move a leg, or being blind in one eye. See Rog, Burgess, Mottershead, and Talbot (2010) for a more comprehensive description of MS.

With respect to etiology, there are some identified causative factors that influence the onset of MS, but no clear cause. One important aspect, which is relevant to our method and findings, is the view that MS represents a dysfunction of the body's own immune system (Rog et al., 2010, p. 5f).

The prospect after a diagnosis of MS is progressive disability for more than 80% of the persons affected; Within 10 years of diagnosis, a wheelchair becomes indispensable for approximately 40% of these patients. Yet for some of them, there is hope: "A minority, [...] those with so-called 'benign MS' [...], acquire[s] no significant disability over many decades of the disease" (Scolding & Wilkins, 2012, pp. 1–4). Furthermore, MS "is a condition known for its complexity, unpredictability and uncertainty [...] and for the [...] people diagnosed [...] this uncertainty will be difficult to live with" (Rog et al., 2010, p. XI). This quote captures some essential aspects that are relevant to this paper. Following this specific explanation of what a diagnosis of MS is meant to cover, I would like to present a subjective theory of health and disease.

2 *Psychological background*

The "*Common-Sense Model of Illness*" (Leventhal, 1987, as cited in Petrie & Weinman, 1997, p. 157) contains five aspects of the mental representation of a given disease: *identity*, *cause*, *time-line*, *consequences*, and *controllability/curability*. *Identity*, as a first component, consists of the names and labels one collects from medical terms, symptoms, or perceived changes. As the term *cause* indicates, the second aspect concerns the subjective conviction as to the cause of the illness. These personal, "lay" ideas need not correspond to the facts comprised by "professional" scientific knowledge (Hale, Treharne, & Kitas, 2007, p. 2). *Time-line* is referring to the predicted or assumed duration of condition. This conviction can be altered over a period of time; for example, when

¹ Pseudonym

personal belief in an acute condition has to be changed to acceptance of an obviously chronic one. The expected *consequences*, or how an illness will affect the patient's lifestyle, independence, and the ability to walk, see, etc., are a further facet of the Common-Sense Model. The last issue concerns the *controllability* and *curability* of the condition, and, in particular, what an individual can do to improve the symptoms, contribute to healing, and the like (Hale et al., 2007, p. 2).

As a whole, these representations can help a person make sense of the changes in their bodies (especially the symptoms), and they may prime coping actions (Hale et al., 2007, p. 2). So, for example, if a person is convinced of his or her potential impact on the progression of the illness, he or she will initiate a greater number of individual actions to deal with it. What I sought to find out in this analysis is how a person with a given diagnosis would determine her way of life; more specifically, with a focus on the way Hanna dealt with her diagnosis and with the progression of the I-illness relationship.

3 Method: How to approach a person with a slowly progressing disease

After my first readings of the MS literature and related topics, I had to deal, simultaneously, with a deeper understanding of my prospective thematic area on the one hand, and with the concrete framework conditions of the upcoming interview on the other. I will now describe the parallel trials of getting acquainted with subjective theories of diseases, and scheduling and designing the interview guidelines.

To begin with, I decided not to read any theoretical background about the diagnosis of MS before the interview, so that I would not have been 'primed' in a single, default way while listening and transcribing. As a matter of course, I read about MS to gain relevant background knowledge, but only after the interview.

Searching for an appropriate way to conduct the interview required special sensitivity to the circumstances of the interviewee's life course. My research interest referred to the consequences of a particular diagnosis. Nevertheless, I did not want to ask direct questions (e.g., "What do you think of the consequences your diagnosis had for you?"), because in doing so, I would only have received direct answers — in other words, I would have been limited to the analysis of generalized meaning signs (Valsiner, 2016, p. 17). In order to study the "'Hyper-Sign' ordered level of psychological phenomena" (Valsiner, 2016, p. 17), I tried to address this level with the open narrative-generating question or request, "Bitte erzähl mir Deinen Lebensweg." [literal translation: Please tell me your "path of life.", which – in German – invites to talk about the developmental trajectory/life course]. If, after some questioning (which tends to stimulate the research participant for sustained storytelling), the output was not about the issue under discussion or did not contain sufficient material, I could still question the subject directly about certain topics.

When it came to defining my interview style, the narrative interview (Küsters, 2009), and in particular, the biographical interview (Fuchs-Heinritz, 2009) seemed to fit. Indeed, during

preparation of the interview guidelines, I was oriented towards phenomena that are ordinarily included in a biographical interview.

Another methodological aspect I thought about was the moment of starting and terminating the audio recording. Throughout the recording session, an imaginary audience is 'present,' and therefore, the moment of turning off the recording device can be perceived as the conclusion of the official performance, at which point everyone can resume acting 'normal.' Therefore, it is not surprising that some participants have revealed important details of their stories after the taping session ended (Fuchs-Heinritz, 2009, p. 274). To address this potential issue, I decided to start the recording already in the opening phase of the interview after establishing informed consent, thus before the first 'real' question/stimulus, and stop it minutes after the last 'official' answer in the interview. In addition, I noted down my impressions and observations after Hanna left.

The interview took place in the evening, in an office room of the Sigmund Freud University Campus in Berlin. The first stimulus-question in the interview was: "Please tell me your path of life." (see above). This was followed by counter-questions and replies:

- "When/Where should I start?" "You can start whenever/wherever you want."
- "Oh, that's quite a lot!" "We have plenty of time."

Mayring's "Qualitative content analysis," and, more precisely, the content-structuring approach (Mayring, 2003, p. 90) inspired my method of analysis. In this procedure, it is essential to structure the raw data, due to the determined-content criteria (Mayring, 2003, p. 90). However, during the analysis process, I realized the need to develop my own strategy, because of the various dimensions set out in theory. These criteria guided my analysis of the transcript. At the end, I cannot claim that I strictly applied Mayring's approach. Nevertheless, I have disclosed my procedure within the sections theory, making the method and findings as transparent as possible.

4 Researcher and responsibility

The reading, "An introduction to partnership in research" (Bibace, Young, Herrenkohl, & Wiley, 1999) further led my positioning towards the research subject. The authors point out the common attitudes of psychological researchers towards the persons interviewed. The word "inter-view" in and of itself indicates its dialectic, collaborative aspect in producing data. So, as a logical consequence, I changed the terminology from the "subject studied" to "the research participant" (Bibace et al., 1999). I preferred this term, first of all, because of its active and contributing connotation, and secondly, because I realized that sending a message of acknowledgment to the participant would, in terms of encouragement, increase the value of her contributions to the research.

The previous step included a shift of stance: from seeing myself alone as the expert, and the research subject as a layperson who could add raw material for my analysis, to viewing my own participation as that of a partner and thinking of the research participant as an expert in terms of her living

environment (Valsiner, 2013, p. 9f). During the interview, I had a feeling of responsibility, combined with a wish to utilize, in a respectful manner, the account that Hanna would provide. This means that I wanted to avoid any approach that would place my concepts above her stories in importance, rather than carefully and precisely examining the inherent generalizabilities.

An interesting incident that occurred both before and after the interview was a question or concern on the part of Hanna as to how or whether she could answer in a 'correct' and productive way within the research conversation. Even afterwards, after more than an hour of sharing her story, she wondered whether her input would be suitable for me. In the situation before the interview, I perceived that Hanna's unease was not useful in terms of the open, casual, and therefore, narration-generating atmosphere of our meeting. My reaction was to state that it was my responsibility and my task — not hers — to make something fruitful out of her account. In our exchanges afterwards, I said the same thing. Whether or not my way of dealing with her concerns proved valuable will be discussed below.

5 Findings

In our interview, Hanna talked about herself and what she had experienced over the course of her life. To apply Leventhal's Common-Sense Model (Leventhal, 1987, as cited in Petrie & Weinman, 1997, p. 157), I will outline each of the model's five aspects (deductive approach) and quote the appropriate transcript passages (sub-themes, inductively assessed aspects), if applicable.

5.1 Identity

With respect to the theme of *identity* and how Hanna labels her illness, I had to open up the scope of the explanation in terms of a time perspective, because of the change in identity that that took place in Hanna's life. The key to the identity aspect of the Common-Sense Model lies in the moment of getting the diagnosis. In the transcript are several instances in which Hanna vividly illustrated her immediate reaction to receiving this news. They present her as first handling and then struggling with labels and names, but especially, wrestling with the state of being ill. The following selection of phrases (in translation from the original German) provides an overview of her statements about this process. I have tagged some words in italics to highlight them.

33 in former times *I did not want to take a look at it*, the same with the diagnosis,
34 when I was 16, that was for me, like, "Um, *I don't have it*, definitely, I don't have
35 it," but, you know, I was in the hospital twice a year in the first three years.

542 I did always push it away (...) I kept it always really *covered up*

559 I *didn't give it any space*, in any way

In these passages, several aspects of her denial become clear. First, her immediate reaction was to refuse the diagnosis as reality. She herself stated, ironically, that even though she stayed in the hospital twice in the first three years, she protected herself (or her “self”) by rejecting the diagnosis. Analytically, this is a claim about the self, one that is made as part of the I–illness relation in particular, and which will be dealt with below in connection with the I–body relation. Following the diagnosis, Hanna enjoyed productive years filled with work and an education in the textile business, changed her location several times, and cancelled a program of study.

Then, 12 to 13 years after the diagnosis, the phase of denial (my term) ended, gradually and subtly. Next, over the last two or three years, a phase of acceptance (also my own terminology) began. Some direct quotations from the transcript are meant to underline this development.

128 the last time was two years ago, and the worst was that I couldn’t feel my right leg at
 129 all. I only had partial sensory disturbances, but still was able to walk. But this time I
 130 couldn’t sense it at all, and that was an *incredible shock*, and I think this contributed
 to the further development [of accepting the diagnosis] in the last two years.

526 I have the feeling that about three years ago I began to be open about the illness
belonging to me in a way

29 And I have the feeling that for the first time in two or three years I am closer to
 30 finding myself (...) and that was *unbelievably good*.

39 And I have the feeling of now really starting to take a closer look at it and this is
 40 really *healing* (...), just salutary, and I am happy that it starts to rest inside me

851 and next I just talked about it as being entirely natural, and it is curative to really talk about
 it

531 Okay, *it belongs to my life* somehow.

These few quotes from the transcript demonstrate the depth of Hanna’s experience of what has changed, and how it feels to begin to accept the illness. Impressively, she states that it belongs to her, and to her life; she starts to take a closer look at it, the MS “starts to rest,” inside of her, she feels that she has found herself for the first time in life, and that this is “healing” and “unbelievably good.”

The transition was both subtle and triggered. As Hanna illustrated, a severe relapse in which she could not sense her leg became a releasing point that initiated further development in her gradual acceptance of the illness. The way she talks about herself in relation to the diagnosis/disorder has changed. Nevertheless, to complete the aspect identity, a third part has to be mentioned.

This sequence is about the I–body relation, which plays a crucial role in Hanna’s story of dealing with MS. The first quote refers to the time after the diagnosis, when Hanna thought about her future prospects. More accurately, she told me about external claims that had been made about her.

70 “Okay, you’ll end up in a wheelchair so you cannot move anymore” (...) and I

71 thought, “I cannot, with such a diagnosis I will not be able to work.”

This external claim, which was made by other people, strongly influenced her. She had to give up dreams of working with her body in dancing or something similar, due to the claimed future prospect of being unable to walk independently. In this situation, an external assertion made about her became relevant for her future plans, and thereby became an internally believed or affirmed statement.

62 I am really grateful for my body being *unbelievably steadfast*

450 But it is this feeling, uhm, of *my body, it is an immune disorder, and my body eats*

451 *up itself somehow*

452 (...) and, you know, trusting myself, well, trusting myself when my body does

453 something I don’t have in hand is difficult (...)

454 This is and probably always will be an issue for me, *my body is doing something,*

455 *which is not good* and I must trust it in general (...)

Yes, *trust*

250 and for me this body is *fascinating* (...) it’s unbelievable how it — it works all together

820 it is just an *appreciation* of this, towards the illness

As a noteworthy point with respect to identity, Hanna described the illness and what happens inside of her in drastic words, such as, “My body eats up itself somehow.” As mentioned above, the disease development of MS includes a dysfunction of a special part of the immune system, and these words are her individual representation of what happens.

In the following passages, much more information is given about Hanna and her relation to her own body. When connected to the quotes from the section of acceptance given above, it becomes clear that Hanna arrived, was more relaxed, and accepted “it” (MS) as “belonging to her life.” In addition, as a result she experienced a different sensation, of literally feeling good in her own skin.

To illustrate this process in a perspective consisting of two different views: In the first view, it is as if she stands in front of something disagreeable and keeps both hands defensively in front of her body, calling out, “I haven’t got it, I do not want you,” immediately turning away. In the second view, having gone through the process of acceptance, she can be imaged as looking down at her own body, which she sees as something that is not alien, but hers, and even to be trusted as a part of this relationship. She feels good and comfortable being herself, and getting to know her own body better. This includes learning which behaviors have good or bad consequences, noticing what is valuable for her and what she can do, and realizing that her confidence in her own body is growing.

The dichotomy expressed by this picture (denial vs. acceptance) does not mean that either one or the other is present. As Hanna states above, the striving and toiling in dealing with her limitations or with “the things her body does” was, is, and probably always will be an issue for her. Both denial and acceptance are, obviously, parts of her truth and her reality.

This means that while Hanna first perceived MS as an external threat from which she had to defend herself, the years of dealing with MS made it more and more a part of herself and of her life. Now, she can even acknowledge the disorder, as is shown through the last quotation given above.

5.2 *Time-line*

The following three quotes concern *time-line* — the third aspect of the Common-Sense Model — and are followed by an explanation.

96 I’m living now and I don’t know how long I’m going to be able to live like this.

97 Therefore (...) I want to live now and (...) I want to be relieved

873 the diagnosis was made 15 years ago, I live the way I live, and I think it is like this,

874 after about 10 years, if the progress is good, it remains, that is, um, exactly

444 well, this year I had my 15-year anniversary — I didn’t celebrate it

The aspect of time-line is inherent in all three quotes, but it is expressed in different ways. Knowing how MS progresses over time, as outlined in the previous paragraph, the question about the anniversary is an interesting one. Especially in the case of MS, future perspective is linked with fear, forecasts, and hope. Because of its unpredictability, which was mentioned at the beginning of the theory chapter, MS goes along with uncertainty, of not knowing how the disease will progress. So, as

the person lives on while reasonably managing the progress of the disease, hope can grow in terms of thinking that “it will not become much worse.” This hope can be detected in the middle sequence above (873–874).

In this thematic area, the past, the present, and the future come together. Or, to put it another way, Hanna’s claim of what her perspectives have been in the past, how she thinks at the present time, and what her dreams and ideas of the future are now, merge in this aspect of time-line. Although the development of the identity aspect is contained within the time-line aspect angle as well, I will not replicate what I have already presented in the section on identity.

5.3 *Controllability and curability*

In the following assertions, Hanna states what she can do to improve her symptoms and contribute to healing.

253 I believe it has to do with a distinct way of living or attitude to life, I think

254 I am pretty convinced that disorders want to tell you something and, um, if you don’t

255 listen to, it will be —

123 And, um, it’s interesting, because *this disease tells me much, if I pay attention* and

124 just listen, listen to my body, it tells me and I understand the relapses I had in my life,

125 I comprehend why.

126 It is like this — that I went beyond my limits, and did something so that my body

said: “*Eh, no, that’s enough.*” Well, it did show me the limits and this was its

possibility to express it.

Here, Hanna’s opinion as to the controllability of her illness can be spotted easily. She interprets or uncovers the symptoms as messages, which she can read carefully and which she should listen to responsibly. Construing MS as a body’s internal alert system (“Eh no, that’s enough”) has some advantages. The relapses are not completely inexplicable, but among other things, they are consequences of overload. During and after the episodes, Hanna knows that it is up to her to pay attention, and above all, it is then clear that she can take better care of herself, so that the attacks do not come on, or only rarely. To sum up: The better she deals with herself, the fewer relapses she will have, and vice versa.

5.4 *Sense*

To summarize the previous sections, I specified the aspects identity, time-line, and controllability/curability in detail. Additionally, I could not find any clear evidence in the transcript

about her conviction as to the causes of her disease. Finally, I decided not to outline the consequences chapter independently, because, first of all, it was subliminally inherent in all three of the other sections. Secondly, due to the development of Hanna's perspectives over time, the representations with respect to consequences have fostered a change, in equal measure, to the other aspects as well, such that any explanation would have seemed redundant. The last point of the Common-Sense Model, the perceived sense, which partly derives from every other aspect, will unfold in the following transcriptions.

665 At the last time I thought: "Hey." It is like — I can see it only in the last few years —

666 a warning shot telling me, "Hey, I can be happy that I'm living my life the way I do."

113 But, I believe, on the other hand, it was good that I had this thing, regarding MS, this

114 "I don't have it, I don't have it." That is why *I continued living the way I did*.

158 Nevertheless it's enthralling, because it is always like, I sometimes have a feeling of

159 everything fitting together (...) and sometimes I have a feeling of standing there and

160 thinking: "Okay hey, everything I did, everything I dealt with, unites somehow and it

161 is a (...) pleasant feeling (...) whatever will come of it, but, nevertheless, it is Okay, yes...."

These quotations contain a meaning-making process of "having the feeling that everything fits together." It is along the lines of the impression of wholeness and meaningfulness. The last sentence is remarkable. It reveals a deep faith that whatever the exact outcome may be, it doesn't matter — it will be all right.

In the discussion below, I will make reference to this section in order to examine the process of meaning-making that takes place during an interview.

5.5 *Contradictions*

These last findings focus on contradictory statements found in the transcript. Although some statements of the research participant contradict each other, they are, nevertheless, valid and valuable for a deeper understanding of the transcript. Alongside the tension between accepting and denying the diagnosis, the following example expresses the participant's wish to treat herself in a good and healthy way.

The first statement is an answer to the question about the possibly good impact MS had on Hanna's life:

784 I think it makes me really look after me. That means, even in simple things, for
785 example, nutrition — okay I told you what’s the matter with smoking (we both
786 laugh). Um, but....

787

788 *Interviewer:* I won’t analyze your way of life, how healthy you are or not.

789

790 I mean, it is like, I believe that I look after myself attentively, but, now when I speak about
that, I think: “Hey, sometimes I don’t look after myself cautiously at all.”

In this sequence of the transcript, Hanna narrates how she treats herself and her own body with regards to a healthy lifestyle. The moment she recognized the contradiction between smoking cigarettes and talking about her own healthy attitude, we both laughed. This can be a remarkable finding, because behavior at the moment of becoming aware of the inconsistency of two attitudes is important to analyze. Laughing can be a way to dissolve this kind of cognitive dissonance. Further interpretation and progression of ideas with respect to the topic of contradictions will follow in the Discussion.

The second sequence transcribed below reveals Hanna’s wish to be seen in in a state of neediness, and her wish to receive help and comfort. At the same time, she describes her stubbornness and her rebellious behavior, and the fact that she would not have accepted any professional help anyway.

514 *Interviewer:* Have you had people around assisting you, especially regarding the
515 grave prospects, or the “In x years you will be in the wheelchair”?

516

517 *M:* Mm-mm (meaning “no”), (...)

518 I believe this was the issue missing for me, because I never [voice becomes shaky,
519 weeping] really [talked] to someone. Apart from that, I repressed it a little [sniffing],
but *I never* really [*spoke*] about it *with anybody*

535 So I believe this is the aspect of me being really stubborn, and in the past I have been
536 very stubborn, and I think, if anybody [sniffing] like my parents or whoever, would
537 have told me “Hey, go and work through it or whatever,” I believe I would have
rebelled against it. They could have done what they wanted. [sniffing]

588 and then, my mother left when I was three.

589

590 And um, sure, all of it was just friction and I believe it was just like that, I was sitting

591 there, and I was living in a shared apartment and sort of completely mature on the one

592 hand, and on the other hand not at all, and it is like, “Eh,” I do really believe, “Eh,”

593 nobody was interested in me (laughing). *“Take care of me, damn shit.”*

594 Yeah, I do really believe, it is like, yes

595 And all of a sudden *everyone was interested*

In these quotations Hanna describes differing desires — met or unmet — and we may observe how she “jumps mentally” from one aspect to another. She has been mature or not mature at all, she wanted to have awareness and received it, but in a way, she had nobody to talk to, and if one of her parents had told her to go to a professional to talk about her condition, she probably would have rebelled against doing this. Here, the simultaneous presence of contrasting aspects in her narration is obvious, and needs further discussion.

6 Discussion

After a detailed analysis of the findings, it is crucial to discuss some selected aspects. First of all, I would like to complement my previous description of the research process by exploring some important aspects. During the process of reading, preparing, concretizing, interviewing, transcribing, commenting, reading again, analyzing, and finally, writing, there were several bifurcation points that guided the direction of my work. The acquisition of knowledge during the research process was not linear, but periodic, and the research was influenced by many data sources.

To give two examples: My impression of “empirical data” changed crucially during the transcribing process. As I moved forward within the audio recording, I recognized many examples of how I, as a researcher, influenced the “data collection” with my individual interests, my personal charisma, my way of asking or not asking questions, and even with the pitch of my voice. This means that the “derived data” were not “objective,” but an outcome of an interpersonal encounter between three interlocutors — me, the researcher; Hanna, the research participant; and an imaginary audience in a specific time and place.

The other example is that the data sources that influenced this paper varied, ranging from lectures over personal readings to conversations with uninvolved third parties.

Continuing these thoughts about unattainable objectivity, the interview and thus this project paper do not and cannot achieve the “status” of an objective observation as visualized in “...Thomas Nagel’s brilliant oxymoron ‘view from nowhere’” (Nagel, 1986; as cited in Daston, 1992, p. 599). Instead, the

project paper tries to communicate, in a clear fashion, the whole research process, with the aim of making the results comprehensible to the audience. As Kant describes it:

The touchstone of belief [Fürwahrhalten], whether it is [objective] conviction or merely [subjective] persuasion, is thus, externally, the possibility of communicating it, for communicability is made possible both by the shared rationality of minds, and the shared object to which the idea refers (Kant, 1787, as cited in Daston, 1992, p. 607).

Linked to this issue, it would be appropriate to reflect critically on my understanding of “reality,” and, more precisely, how I treated the transcript. In the interview, the research participant constructs meaning during the narration, and so, treating spoken words as hints about underlying psychological truths is questionable (Potter, 2001, pp. 316–317). Within this framework, the point raised can be named but not conclusively discussed.

Another aspect that should be discussed is the *imaginary audience*. Hanna knew that at least part of her narrative would be presented to a real audience: the students in my classroom and their supervisors. Among the students in this class was one of Hanna’s friends, who enabled this contact with me. In the course of my analysis, I failed to spot any hint that Hanna wanted me to falsify part of the transcript in light of this awareness on the part of the future audience. On the contrary, Hanna described her ability to talk with this friend about me, and how my voice made a pleasant impression during our first telephone conversation. Hence it is plausible to interpret the friend’s role as supporting, and the audience as not having a detectable effect.

Further on, the influence of the pitch of my voice and, in general, of the *empathy* I showed to Hanna are worthy of consideration. This is in accordance with Fuchs-Heinritz (2009, p. 227f): “The most effective helpers and the best tools of anthropologists are sympathy and compassion for the people he studies.” During the research process, I became aware of the auxiliary effects of my approach, which was to show empathy, to have a genuine interest in the research participant, and to make her feel comfortable. In other words, if I had not shown much compassion and the ability to connect, my research interview, the transcript, and therefore, the analysis and the results would now be different, and probably less substantial.

“Partnership in research” must be critically specified. Seeing as I wanted to establish “another way” of research, my final reflections were disillusioning. What started with an honest change in my inner attitude towards the research participant had been confined to what was largely a change of terminology. Due to the research participant’s failure to answer further questions as part of the auxiliary consultations during the analyzing and writing phase, I became the main interpreter, with full responsibility for the analysis. Because of this shortcoming, future studies must do better at implementing participation in follow-up research.

The last aspect to be emphasized is the *coexisting contradictory attitudes, thoughts, and feelings*. Especially in the last section of the results, rapid changes in attitude can be found. A wide range of themes characterize this sequence: the request to receive the needed attention, the care she missed, her sorrow in realizing this, and finally, her admission that even if help had been offered, she would not have accepted it.

In this example, the coexistence of differing human feelings and thoughts is vividly expressed, and clarified as not being mutually exclusive. This means that contradictory inner movements can coexist at the same time, and perhaps even because one attitude is revealed, the conflicting one pops up. For example, because of Hanna's sorrow and sense of what was missing back then, her defense of her father and brother and the avowal of her own stubbornness emerged to moderate or reduce the

Here it is appropriate to mention Frenkel-Brunswick (1949), as cited in Furnham (2015, p. 2) and the personality trait *tolerance of ambiguity*; or, as it is called now, uncertainty avoidance. One aspect linked to this is flexibility, which means the possibility of allowing uncertainty to exist, of a non-rigid and non-dichotomizing approach of defining categories. How and why this aspect is of special personal interest to me appears below in the Conclusion.

7 Conclusions

This section will pick up the earlier threads and draw on them to gather insight towards future research directions, particularly with regard to the coexistence of contradictions. First of all: In the section "Researcher and Responsibility," I dealt with a rather general issue concerning the researcher–interviewee relationship and how change may be fostered towards more integrity and equality. As a result, I changed the term "research subject" to "research participant." Secondly, I became aware of my altered inner attitude with regards to respecting the participant as an expert in her own life experiences. In the Discussion section, I revealed the shortcomings of my implementation.

It is not surprising that the symptoms and relapses of the participant's MS were challenging to cope with. Therefore, the first years of living with the disease were shaped by several hospital stays and, at the same time, a denial of being ill. Over the course of 10 years, and largely due to a prolonged hospital visit due to major symptoms, such as partial numbness, the participant recounted a change in her thoughts, feelings, and behavior in handling MS. She began to accept MS as a part of her life and her body, even though she described what was going on as "my body eats up itself somehow." In the recent past, she seems to have gained a state of being comfortable with herself, of finding herself, in a manner of speaking, and making peace with her illness.

In summary, the simultaneous existence of contradictions is of special interest to me, especially with regards to further research. In these findings, I presented the stance towards the diagnosis as having changed over time outside the boundaries of either–or logic. Instead, the analyses revealed that opposite positions can be in place at the same time. In this case, the contrary stances concerned both accepting and refusing the reality of having MS.

Furthermore, the other two examples of different, competing inner attitudes revealed how important analyzing the particular reaction was to the realization of a contrary situation. Laughing followed by swearing, or citing a healthy attitude and then confessing that she smoked cigarettes, could have reduced tension for Hanna. Nevertheless, this behavior's true function in terms of the

reaction and its effects must be investigated more precisely before a hypothesis can be verified or rejected.

The results of this study lead to a number of general questions. For example: How were contradictions in religion, medicine, philosophy, and psychology seen and dealt with in the past? How do reactions in the moment of realizing the contradiction differ from each other, and what is their particular role? The first question is a rather broad one. To be more specific, I am curious as to how either—or logic once predominated in different societal dimensions, or how it was possible to allow oneself and one another to think and feel paradoxically at the same time.

Another crucial question is: How can contradictory feelings and thoughts be seen as an essential element of human life? This question requires a positive perspective in figuring out the significance of contradictions.

To conclude this paper, I would like to return to Kant's idea, as quoted above. Because I cannot influence the "rationality of minds" among those who read of this paper, I have tried to process the shared object in as accessible a way as possible. That is the reason I have added numerous citations of the transcript to the present study. The touchstone of belief in this paper lies in the traceability and plausibility of the underlying research.

Compliance with ethical standards

The author declares that he has no conflicts of interest. All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

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