CHAPTER 6

Narratives that matter. Illness stories in the ‘third space’ of qualitative interviewing

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In the process of narrative interviewing in the medical field, intense relationships between interviewer and interviewee can develop and participants are often willing to reflect in a committed and multi-faceted manner about their illness experiences and their biographical meaning. Based on observations and data from the website project DIPEx (Database of Individual Patients’ Experiences), this effect of the situation of narrative interviewing is analyzed in terms of positioning and contextualization activities of interviewers aimed at deconstructing hierarchical imbalance and establishing an expert identity for the interviewee and his/her illness experiences. The evolving situation with its role changes and openness to identity work is compared with the concept of heterotopia and regarded as a deliberately created and transient ‘third space’ to explore new subject positions for the interviewees. Advantages and ethical as well as methodological dangers of this approach to interviewing are discussed.

1. Introduction: Experiences from the world of qualitative research interviewing

The following considerations on illness stories are drawn from a very special experience which interviewers in our website project DIPEx (Database of Individual Patients’ Experiences; see Section 2) have noted and which have also been confirmed by other research interviewers doing open, qualitative interviews in the medical field. We share the notion that in the process of interviewing with a technique which gives space for and favors narratives a highly personal, intimate climate develops. More often than not this draws the participants together in an atmosphere of deep emotional involvement and a sense of moving far beyond the boundaries of an ordinary meeting of two strangers talking about health problems,
let alone of a research setting. Of course, this does not happen with all interviewees and all topics, but it occurs often enough to reflect on it. Participants share stories which give deep insights into their personal worlds of illness and often into their whole life stories, their hopes and sufferings, and their beliefs. During the interviews, they often start to reflect upon their illness experiences in a concentrated and up-front way, developing new understandings, finding inspiration in biographical connections and musing about causes and conditions, which, as they remark sometimes, come quite as a surprise to them. Sometimes they fetch and show photo albums or meaningful personal belongings to give a personal and lively background to their telling. The meetings often culminate in cordial, moving farewell scenes. Interviewers are frequently hugged and receive expressions of gratitude and intimate understanding. Sometimes they are sent away with goodbye presents ranging from home-bred fruits to hand-made objects. Interviewers themselves feel deeply involved in the stories, sometimes burdened with the sufferings of their interviewees, but very often filled with respect and admiration for their interviewees’ accomplishments to lead a meaningful life in the face of hardship. After the interviewing, relationships may be maintained by e-mail, letters or phone calls and may even grow and last for considerable periods of time.

At first sight, these phenomena do not tend to surprise experienced qualitative interviewers who may find them quite common and easily explainable. The setup of the interview implies that interviewer and interviewee meet for some hours and share highly intimate, meaningful conversations and stories of suffering and perseverance; methodical guidelines laid down for qualitative researchers particularly aim at creating this atmosphere of intimacy and understanding to make the participants get close to the unimpeded flow of memory and to obtain authentic data. At second sight, however, these encounters, are quite astonishing and therefore looking into their components and prerequisites with regard to social and interactional theories is worthwhile as these encounters display an almost explosive unfolding of mutual understanding, sympathy, new insights and the notion that something important and decisive is happening. As research interviewing is first of all a product oriented towards obtaining useful and adequate data for a research program, and describes the setting and behavior of participants mostly in the light of useful and methodologically underpinned interviewing techniques, these interpersonal side products of strikingly intense relations are rarely the object of scientific consideration, as they develop and take place beyond the default setting and at the edges of what is included in the documented data. For researchers, however, they may be fascinating and, at least in the beginning of their scientific career, also quite overwhelming. Sometimes, newcomers in the field of research interviewing may even feel guilty for having lost professional distance or are afraid of being manipulated by their participants.
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This article tries to shed light on what is going on in such situations. Firstly, we will briefly relate our ideas to relevant considerations in some textbooks of qualitative research interviewing and show how they touch the very core of qualitative research methodology and ethics (Section 2). In order to provide a practical example and to link the issues we want to explore to the actions of the participants, we draw on the data collection process of our website project (www.krankheitserfahrungen.de) as it is considered to be exemplary (Section 3). After describing the aims of our research program, we will show how these phenomena are connected to our procedures of framing the research process, of inviting and interviewing participants, and to the aims of the project (Section 4). As the latter are in sharp contrast to their former experiences as patients in medical settings, we will take a short detour to the role assignment and identity changes patients usually experience when they come into contact with health care institutions (Section 5). We will then try to reformulate the process of meeting and getting involved in the interview by relying on positioning theory and we redefine the context of the interview settings as a ‘third space’ in a special sense (Section 6). Finally, we want to point out opportunities as well as problems to be considered in these demanding and delicate encounters of doing qualitative research in the medical world (Section 7).

2. Qualitative and narrative interviewing: Aims and contexts

Narrative interviewing techniques aim at gathering the interviewee’s own perspective in its experiential and biographical form communicated in stories. They draw on the whole array of narrative theory as an epistemological underpinning with its stress on the narrative basis of experience, biography and identity work (Czarniawska, 2004).

Structured interviewing in a quantitative approach aims at “reproducing reality” in a valid, reliable and objective way. In contrast, interviewing in qualitative research is targeted on participants’ own perspectives, experiences, meaning structures and action orientations. Its methodological and methodical vantage point draws on interactionist and mainly constructionist conceptions of social reality and truth, focusing on meaning making processes and their dependence on relational and contextual aspects of the situation in communication (Kvale, 1996, pp. 10–13). Thus, contextual aspects of building and shaping the conversation and the impact of language need to be explored in detail. A close investigation of how language use, linguistic strategies and negotiations construct reality and work on a shared understanding between the participants is crucial to leading and analyzing interviews (Hollway & Jefferson, 2013; Mishler, 1986; Wengraf, 2001). Qualitative interviewing is based on the assumption that any conversational input is reflected
in and forms part of the further contributions and the emerging text as a whole. So, in contrast to quantitative interviewing, the task of the researcher is not to disappear as a person behind the field manual, but to accompany and support the interviewee’s self-explorations and memory work and to enhance their narrative endeavors without being manipulative or suggestive. The interviewer’s role and impact has to be taken into account in a systematic way in order to reconstruct the participant’s perspective. From research interviewers, it demands a high degree of reflexivity and sensitivity to realize and control their own part in the meaning making process of the narrator. They try to build an atmosphere of trust, allow the participants to explore their memories and give them room to present their perspective without interruption. Interviewers support and validate the narratives without evaluating their content, and refrain from critical remarks on a verbal as well as on a nonverbal or paraverbal level.

All of the textbooks mentioned share a deep concern about ethical issues, regarding the highly personal and intimate approach when interviewees are offered a trustful relationship where they feel safe to disclose biographical details, emotions, values, identity negotiations and action orientations.

3. An example: Practical aspects and minutiae of qualitative interviewing in the DIPEx program

To illustrate and plunge deeper into the special phenomena described above, we want to introduce the data collection process for the websites which share the aims, ethics and methodology of the international DIPEx (Database of Individual Patients’ Experiences) program as a prototypical example.

The DIPEx projects which are undertaken in several countries all over the world (see www.dipexinternational.org) present patients’ stories of illness experiences on internet websites in modules about defined conditions (Herxheimer & Ziebland, 2008; Lucius-Hoene, 2012). Considering the patient as an expert for his or her illness experience, the stories are triggered by means of narrative interviewing in a maximum variation sampling. The aims of the websites and their underlying research projects are to deliver easily accessible information and support for fellow patients, relatives and interested users, given from the varied viewpoints of people with first-hand experience of the impact of illness on their daily lives and of being diagnosed and treated in medical institutions. The interviews are also widely used in teaching and training in the field of medicine to convey the personal experience of being ill in contrast to the medical viewpoint (Toombs, 1993), and to enhance empathy and understanding. They also provide well-researched qualitative data for further analysis of patients’ experiences with illness and the world of
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medicine. The interviews are carried out by persons who have a background as social scientists, psychologists, or are medical professionals. The interviews are obtained with open in-depth interviews, with techniques that are non-restrictive, highly supportive and nonjudgmental and aim at eliciting narratives. The topics and the extent of disclosure are largely in the hand of the participants (Ziebland, 2013, p. 40). As participants are very carefully informed about the aims of the project and of the modes and variations of how their interviews will later appear on the internet, they are well aware that the interview may partly be published for an unlimited internet audience.

Following rigorous qualitative analysis, the topics of illness experiences are presented on the website and illustrated with short video, audio or text clips from the original interviews. A jointly composed summary of the personal story of each contributor is offered.

The data collection procedures for DIPEx modules (as well as the further steps of analyzing data and constructing the website modules) are put down in the Researchers’ Handbook (Health Experiences Research Group, 2014), which is continually revised and serves as a binding methodological and methodical basis for all DIPEx teams. For the interviewing technique, the handbook refers to other qualitative research textbooks. However, the directions meticulously point out practical issues of setting the scene, dealing with problems during the interview, making the participants feel at ease, and other aspects of creating a personal and supportive atmosphere. Not only the explicit suggestions given by the handbook, but also the routinely adopted lines of action build a certain ethical and interpersonal framework for the projects which starts even before interviewees are approached. For instance, in the DIPEx groups researchers do not speak of “recruiting” participants for the interviews, but of “inviting” them to share their experience. This changes the message linguistically from a hierarchically higher position of the researchers with a slightly militant connotation to a friendly and cautious request to support the project. Interviewees are regarded as contributing to the project as equals and not as numbers adding to the methodical realization of a research program. In the material used to approach potential participants and professional mediators, target persons are addressed as experts for living with the disease whose experiences may be of highest value for others who suffer from the same condition, for their relatives and also for teaching programs in medical training institutions. Their special expertise is judged as being of the same importance for everyday living with the condition, as medical expertise is for healing. Great care is given to the explanation of the history and purpose of the website as well as to the established consent procedures and other issues of data protection. Contact data for questions and for the identification of the research team are highlighted and interested people are encouraged to call back and ask questions.
When a prospective participant approaches the team, a great deal of care is given to extensive information; the team avoids making persons feel urged or coaxed to participate. He or she is treated as somebody offering a special gift by taking part instead of being a proband or subject in a research setting. It goes without saying that their preferences, e.g. as to place and time of the interview, are considered. Before an interview is conducted, several telephone calls or face to face conversations have already taken place regarding the circumstances of the interview, concerns of the interviewee and to clarify the preferences and motives of both interactants. The interviewers’ first choice is to visit participants at their homes, which, due to the regional maximum variation sampling, can mean hundreds of miles of travelling. So when interviewers arrive, they are very often welcomed as special guests in a hospitable atmosphere. The same ensues when the interview takes place in an institution: interviewers carefully set up an almost private surrounding, offering drinks and biscuits and arranging comfortable seating in order to make participants feel at home and relaxed. Furthermore, choosing a pleasant background for the scene and setting up the video or audio equipment draws both parties together and creates opportunities to cooperate. Before and after the interview, there is a lot of private and informal talk ranging from living conditions, daily news and state of affairs to storytelling about more private aspects of the project. These aspects create an atmosphere which gives priority to wellbeing and mutual concern over scientific professionalism. Once the interview has been transcribed, participants are telephoned and helped to decide which parts of the text they want to release for the project and to co-edit their own personal illness stories for the website.

Follow-up interviews with our participants six to eighteen months after the first encounter about the experience showed that for many of our interviewees, it had been a significant event. Several described it as liberating and helpful to disclose their stories and to be listened to, as illustrated in (1). The following interview excerpts are taken from the modules ‘colon cancer’ and ‘chronic pain’ of the German DIPEx project with its website (www.krankheitserfahrungen.de) and from post-event interviews with participants for evaluation purposes. The names of the patients are pseudonyms. The translations from the German original were made by the research team.

(1) Chronic Pain Module, post-event interview, Amelie Hoffmann
The procedure seemed to be simple and I was given a very friendly welcome, and treated very, very gently, like a raw egg... of course I was excited when I heard they would come to see me at home, this helped a lot because at that time I was not able to go out. It was all very — and when you came I was excited, of course, but it was really cozy and comfortable and I felt very well treated and the way I was treated and the sort of questions
impressed me very much, because I had never before been treated in this way, of course, what I said in the interview the social level, digging deep. And when I closed the door, I was shattered, but overjoyed, somehow intoxicated by some hormones, I don’t know, endorphins swept through my body. It was very liberating, very pleasant. I was over the moon like I had not been for a long time. Like when you write an exam and do well. It was emotions and feelings I did not have any more since I was ill. Well if I could have danced these emotions, I would have jumped over the meadow like a little kid in a white dress…

In order to fully understand what this special set-up of relationships and setting means to many of the participants and how it often takes them by surprise in a positive way, it is worthwhile contrasting it with their experiences when they are institutionalized because of their illness.

4. Patients’ identities in the medical world

Illness interviews done in qualitative research are thematically linked to diseases, bodily processes, physical suffering and to being the object of medical care in relationships with experts and institutions. Thus, patients’ experiences in the medical world are the backdrop and a major source of stories when interviews are conducted. Almost inevitably, what they have experienced can be highly ambivalent. On one side, modern medicine and its protagonists and institutions may have cured or sustained them, perhaps saved their lives. On the other hand, due to the processes of diagnostics and treatment, patients have not only suffered a severe loss of autonomy and control as a result of their illness, but also undergone changes in their self-concept with regard to their social position as a patient. Identities ascribed in the processes and interactions of medical care are more or less limited to roles linked to physical and interpersonal dependency and to the necessary submission to rules and regulations of examination rooms, wards and special care units. On the one hand, sick roles may have dramatically changed since Parsons first coined the term and the concept (Hoefert & Klotter, 2011; Williams, 2005), and modern conceptions of interactions in medical setting emphasize much more patient empowerment, engagement and cooperation. On the other hand, much of the old role patterns inevitably seem to survive and owe their persistency to the fact that there is a structural disequilibrium of power and professional expertise involved, as well as institutional constraints and organizational logics and logistics. When the patients enter medical institutions, they often feel treated like objects, stripped of biographical and personal resources, interpersonal competencies and power to stand up for themselves. The changes in self-reliance and identity when
becoming a patient have been intensely explored in autobiographical, fictional as well as sociological and psychological literature (e.g. Frank, 1995; Hawkins, 1993; Stein, 2007; see also this volume: Diedrich; Gygax; Kern-Stähler & Thiemann), creating their own narrative genre as “broken stories” (Hyden & Brockmeier, 2008), which combine physical, psychological and social damages.

In their predominantly functional, highly technical and goal-oriented principles of organization, medical institutions and relationships can exert a powerful, dominating and rigid influence on identities. They can bring about most powerful changes in personhood, self-reliance, and feelings of self-efficacy. The scope for negotiations of identity can be very small, as patients feel dependent on getting professional help for which there are hardly any alternatives. Examples (2) and (3) show how the interviewees reflected on the emotional distress and ambivalences they experienced in the course of diagnostic and treatment procedures.

(2) Colon Cancer module, Petra Markert
What I realized there for the first time is that I wanted back the control over my life. Because with chemotherapy, first in hospital, then with the chemotherapy you are always in a scheme of things you have to do. You must do this, you must do that, you must have an operation, you must have another operation, you must irrigate the wound, you must take the antibiotics, you must go there twelve times (…) Argh. Always “you must, you must, you must.” I must, I must, I must. And that was really very hard for me to be fixed in a scheme, you must, you have no choice. You must do that. If you want to have a chance to survive, you must do it.

(3) Colon Cancer module, Richard Linde
It was all very interesting – well I don’t want to play it down. On one side, it was this absolute necessity, to know: what they do to you is necessary. If they don’t do it, I will be dead within half a year…. Well, somehow you have to – give away. Which, how shall I say, impressed me – well it was quite a new experience for me, it was something like, this absolute helplessness, this being at the mercy of the situation of the others. Up to the, the hour before the operation, when you have to give away your clothes, all of them, then your glasses, you can’t see any more, then they ask you “Have you any movable dentures?” they have to get out, everything out. And then they give you a tablet, such a tranquilizer, sedative, so that, that you calm down a little bit. And then you lie there, in this hospital gown, and to be so utterly at the mercy of the situation, this was a new experience for me. I had not experienced anything like that before. But as I said, as I said at the beginning: the necessity to do that was clear, there was no question. It was like that.
to responding and reacting rather than being able to initiate actions and speak out. Opportunities and spaces for patients to communicate not only their symptoms and medically relevant complaints but also their personal suffering and the meaning of their illness are extremely rare, up to the point that doctors’ interactional strategies may aim at preventing patients from talking when not asked directly, let alone from telling stories about their existential problems (Bliesener, 1980). Apart from many positive personal experiences in the medical field, our DIPEX interviews present an appalling amount of stories depicting situations where patients felt humiliated, deprived of power and alienated because of interactional customs and professional encounters in health care (Lucius-Hoene et al., 2012). The following examples mirror the interviewees’ indignation and feelings of insult in confrontation with the doctor or careless routines of the medical institutions.

(4) Colon Cancer module, Wilfried Schönfeld
Then I entered the clinic of which I have very mixed feelings. On the one hand, I felt well treated in the hospital, well operated on, well cared for, very well cared for by the nurses. But on the other hand I sometimes felt treated like a piece of dirt. For example, they did an X-ray contrast record. And it was discovered that I had a huge bowel. (…) And because of my huge bowel the contrast medium, they gave to me, didn’t suffice. And because I was large, I didn’t fit in the X-ray table. I had to lie in a sort of bowl, where they could turn me. They ranted and raved because of my size. Then, the doctor complained about the insufficient amount of contrast medium. Then, they ran out of contrast medium and had to search for it. It lasted almost an hour. All this time I was lying bare in this X-ray room, the assistant had a phone call with her friend and told her about her experiences of last weekend. When I got her attention, she placed a tuft of cellulose on my genitals. I thought I was in the wrong film. It is events like this I experienced many times. I did not find them malicious, just thoughtless. And it was this thoughtlessness I found so malicious, well, this kept going on and on – whereas the important things went very well.

(5) Chronic pain module, Daniela Klein
One of them (the doctors) was really fierce (laughs), I thought he was really brilliant (ironic), he really said to me “You know what, don’t go making such a fuss, compared to others, you are much too well,” I think he neither knew how I live or what I do, he knew nothing about me. Then he said: “When you look out of the window, you can see at least twenty persons who are much worse than you are.” I said “Well and now I am much better? I can’t believe it.” He said he had seen a child they had to amputate the leg below the knee, this would be much worse. Then I thought yes, of course, that’s bad for the boy, no question, but everybody has to live with one’s illness, it is bad for everybody, no matter what is your – well there I – I never felt so humiliated and degraded as by the medical experts.
When at the end of our DIPEx interviews, we ask the participants whether they have a special message for doctors, the most frequent and all-pervading answer is that they should take their patients more seriously and talk to them, more often and preferably as equals.

(6) Colon cancer module, Jutta Groß
Perhaps the doctors should sometimes put aside the objective facts and realize that there is a human being sitting in front of them and not see the illness, but sometimes the person, too. I think, they forget this sometimes or they are so involved in their work….

(7) Colon cancer module, Norbert Wagner
In my experience, the reason for judging a doctor in a negative way is always based on the communication level. That you didn't understand, what your patient doesn't know, what you do to him, what he means to you. That's in fact the most important, what you must realize as a doctor, in spite of the hectic rush of everyday life, in spite of any hierarchical quarrels that may go on behind the scene. But in the patient-doctor conversation, the power must flow. Yes, that's where the connection must be created.

These answers seem to mirror a common lack of the doctors to acknowledge their patients as partners, sometimes even a lack of respect, depriving patients of their dignity.

And even without any negative encounters, severe illness itself is “a loss of the ‘destination and map’ that had previously guided the ill person’s life” (Frank, 1995, p. 1). Having to leave one's independent and autonomous self behind when entering the world of physical illness and medical institutions is enough of a shock to leave its traces on identity and self-reliance.

This imbalance of power and the lack of a place to stand up for one's self is especially oppressive when people suffer from conditions which are problematic, unpromising or controversial in the medical world. This may be true for chronic illnesses and life-style dependent health problems, where patients may be considered unable to control their health-related behavior, and it may also be an issue in the case of incurable diseases with no prospect of improvement. Most certainly this imbalance of power is a major point in conditions with vague and unspecific symptoms which are disputed by experts and do not find an undoubted equivalent in the medical system of diagnoses and “real” diseases. These are patients whose stories are problematic and risky in the medical context (Bülow, 2008, p. 131), and yet at the same time being able to tell their story is crucial as they need other people to listen to them and take care of them to make meaning of their contested illness experiences. Not being able to tell one's stories of illness without the risk of being frowned upon also leads to vulnerable identities and feelings of being victimized.
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5. Positioning experiences in the context of qualitative interviewing

In order to take a deeper look into qualitative research interviewing and especially in the DIPEx context as shown in the introduction, it may be useful to consider the settings and procedures in terms of positioning theory and in contrast to the assigned identities in medical settings.

Positioning theory offers an interactional approach to the ongoing constructions and negotiations of selves in encounters of all kinds. According to Deppermann (2013a, p. 2) the concept of positioning goes back as far as Foucault’s notion of subject positions. It was later given a widely used definition by Davies and Harré (1990, p. 48) as “the discursive process whereby selves are located in conversations as observably and subjectively coherent participants in jointly produced story lines.” The concept gained strong empirical underpinning and a dynamic grip on everyday encounters, when fine-grained interactional and linguistic analysis based on conversation analytical and narratological concepts could show how identity work is carried out on the different levels of storytelling (Bamberg 1997, 2011; Bamberg et al., 2011; Lucius-Hoene & Deppermann, 2004, 2008; Wortham, 2001). For everyday conversations Bamberg and Georgakopoulou (2008) pointed out how narrative identity work mainly takes place in ‘small stories,’ fragments of interactional and often collaborative storytelling which accompany our daily encounters.

The concept of positioning aims at the discursive practices which people inevitably use when getting involved in any social interaction. By positioning themselves and their interactants through their specific linguistic strategies, they claim a social space to present themselves and assign corresponding positions to others. Positionings may draw on personal characteristics and identity properties, roles, group categorizations and memberships, motives and action orientations which together construct a locally relevant identity. By analyzing these interactional and identity claims on the basis of the interactants’ linguistic and narrative strategies, the perspective of positioning grasps not only descriptive, but also performative and interactive components of identity work as an ongoing process (De Fina & Georgakopoulou, 2012, pp. 161–171; Deppermann, 2013b; Georgakopoulou, 2007; Lucius-Hoene & Deppermann, 2004, 2008).

As in every interaction in the situation of qualitative research interviewing, positions are constantly revised and negotiated. Thus, interviewers can influence the assignment of positions regarding their participants by focusing not only on the denotational content of the stories and their connection to the research questions, but also by offering undisputed, rewarding and powerful positions within the conversation, especially before starting the interview, which make them feel safe enough to allow self-reflection and memory work. Interviewers’ technical
expertise, experience in dealing with persons in difficult situations and consideration of ethical issues can open a safe space to display aspects of identity which may not have been considered or expressed for a long time. The appreciative, respectful and supporting ways of asking for narratives and the intense and patient listening without interruption strengthens the patients’ sense of the importance of their experiences. The interviewer offers him- or herself as somebody who might someday be in the same situation. The interviewees are explicitly and implicitly addressed as persons who can help others not only by supplying anonymous research data but by their personal testimony, by committing themselves, playing a part and speaking to others with authority. Thus, the listener is not only the interviewer or the researcher collecting data, but represents an unlimited audience, which is implicitly present in the interview situation, i.e. all users of the website who will see the participant’s video clips on the internet, as for instance fellow sufferers, medical professionals and all the people interested in the topic.

The negotiation and building of positions is crucially dependent on how interactants experience and interpret the situation in which the interaction takes place. As in every social encounter, the whole process of contacting, meeting, interviewing and preparing the website texts together is accompanied by providing ‘contextualization cues’ (Gumperz, 1992, pp. 230–232), which deliver the framework for understanding the proceedings as a special kind of situation. We can reformulate the surrounding and preliminary actions of qualitative research interviewing as the partly controlled and partly spontaneous contextualization work of the interviewing persons to suggest special interpretations and prevent others. Right from the beginning of their contacts, researchers try to shape their participants’ perception and interpretation of the interview situation by pointing out relevant aspects of the situation, including much of the interviewers’ own self-presentation. It can be described as avoiding any social inequality in meeting the participants and “undoing” expert roles or a superior status as very knowledgeable or powerful scientists for themselves, independent of their professional background as social scientists, psychologists, or medical professionals. At the same time, participants are addressed as the real experts and witnesses for living with the illness and as the protagonist of the endeavor to explore the world of illness. They are given active parts in the setting up of the interview situation. For instance, when they ask beforehand how much time the interview is supposed to take, they usually get the answer that this is totally up to them, depending on how much they would like to share and how much time they are willing to invest. Instead of being an object of research, they are implicitly encouraged to take over the role of expert and host which is facilitated when the interview is on their own territory, namely at their homes. The setting is organized in a collaborative action, where each of the participants may alternately take a leading part and the
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adoption of role aspects of expert and layperson, host and guest, dominant and submissive actor, person in charge and person in a dependent position may vary and oscillate between the involved interactants. The use of interviewing strategies as mentioned in Section 2 provide opportunities to offer positions for the participants in which they feel appreciated and taken seriously, in which their stories are not doubted, challenged or scrutinized. Even when participants seem to be at a loss at the beginning of the interview and express doubts whether they can meet the demands of the researcher, reassuring explanations that they cannot make mistakes, empathic feedback strategies, intense listening and adequate prompts of the interviewer quickly tend to make them feel at their ease and plunge deeply into the story world of their illness experiences. Although interviewers refrain from explicit evaluations or commentaries on the stories’ content, they convey empathy by adjusting their paraverbal expressions and show solidarity with the experiential world of the patients. So they offer an unrestricted space for personal meaning-making.

6. DIPEX interviewing as identity work in a third space

When taking the interviewers’ simultaneous actions of contextualizing, positioning and supporting before and during the interview into consideration, distinctive features of the interview situation bear resemblance to the idea of a third space or heterotopia. Kraus (2013) uses the concept, which is taken from postmodernist and postcolonial discourse (Foucault, 1986; see Hetherington, 1996, 1998) to describe spaces of otherness

Kraus (2013, pp. 76–78)

To point out the concept, Kraus draws on Hetherington (1996) who describes heterotopias as real social spaces with a utopian aspect, as they allow “for the exploration of subject positions in a place of otherness” (Kraus, 2013, p. 77). Oppositions to the usual attributions of identities in the medical world which are transcended in the interview situation can be seen in categories like doctor/patient, expert/lay person, helper/aid recipient, powerful/powerless, dominant/subordinate, active/passive or experienced/ignorant. Qualitative interviewing conducted with the background of investing scientific and methodical knowledge to safeguard and make public the voice of experience transcends the oppositions which leave only socially restricted, dependent and damaged identities for patients. It opens this

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kind of third space for them to move beyond the restricted roles and reclaim their moral identity as responsible agents. In our borrowing of the term ‘space,’ we not only use it as a metaphorical transformation from a spatial entity, as it is preferably used for the heterotopias in cultural sociology, to a social encounter. We can also take it verbally, that is as a location and a time span which is worked out and offered for the interview and which differs from clinical or research settings. In contrast to other persistent heterotopias, however, it is a transient space, which develops when in contact with the research project, leaving its traces in the more permanent appearance of the interviewee on the internet site. Moreover, it is a space deliberately created and not grown in the margins of dominant societal structures.

The role and sphere of action of the qualitative interview is ideally suited to create this third space, as the interviewer due to his or her profession is in contact with the medical world or a research institution in health care and can partly claim its power. At the same time he/she explicitly dispenses with this power by denying a superior role, handing over much of the situational control to the patients and offering alternative positions to them. This gives room to the patients’ own stories and assigns the power of definition and interpretation normally claimed by medical experts to the patients. The interviewers’ stance has its background in an ethics of being committed to patients’ voices and in the conviction that medicine needs the experiential perspective of patients as urgently as the scientific expertise of doctors. The roles assigned or made available to the interviewees by the carefully set up interview situation afford them the power to take a critical look on the medical system as well as the chance to bring their own set of values and priorities into play. Reclaiming their own story of suffering and healing from the dominant terms and concepts of medical diagnostics and scientific categorization enables them to restore their dignity and sense of agency (Frank, 1995). In their interview narratives, they can explore and find new forms for their illness experiences, which often tend to develop their own dynamics of remembering, reshaping and re-evaluating what has happened. This may even take them by surprise, as was sometimes remarked on after the meeting or in our follow-up phone conversation (Lucius-Hoene et al., 2013). The construction of a free space to tell stories of encounters in the medical field also gives a chance to build up new narrative positionings for themselves as well as other-positionings for their interactants in the stories, thus working on their self-esteem and self-reliance (Lucius-Hoene et al., 2012). Their illness stories can enfold in the way claimed by narratological approaches to medicine and bioethics (Charon, 2006; Nelson, 1997) so that their stories “can breathe” (Frank, 2010), can have a beneficial effect for their identities and matter for their lives.
7. Conclusions

Looking at qualitative research interviews in the medical field as the deliberate and ethically motivated creation of a third space for patients’ identity work gives a theoretical underpinning to the procedures and interactional strategies procured by the research team. In paying attention to their positioning and contextualization strategies, interviewers can work on trusting and open relationships and thus enhance identity work of their participants and the benefits of being able to tell one’s illness story not only as an information for researchers, but also as a means of coping with the disease for one’s own sake (Lucius-Hoene, 2002).

At the same time, research interviewing can be considered not only as a data collection process, but also as an intervention. It leaves an impression on the interviewee, possibly initiating identity changes and opening new ways for self-esteem and processes of meaning making, and may also impact on and challenge interviewers. However, there are some dangers involved in this personalized and committed style of doing research. Highlighting the interventional impact of research interviewing does not mean that it should in any way deliberately aim at such processes of change. This means that the interviewer has to be careful about not pushing his or her own ideas of liberating or emancipative self-changes on the patient. He or she must clearly draw a line to psychotherapy or counselling and not offer help or a lasting supportive relationship in this respect, regardless whether he or she has therapeutic skills or not. Interviewers must be prepared, however, to be explicitly or implicitly asked for help from some of their participants in difficult situations and should be able to point out other directions of getting support.

In its ethical foundations, the process bears much resemblance to the client-centered approach to communication and psychotherapy with its principles of authenticity, empathy and acceptance (Rogers, 1951); yet, it uses different interactional strategies and does not aim at bringing forth processes of personal growth or changes of self-concepts in the patients (although this may be a consequence of the research interview). On the contrary, some of the interactional techniques of humanistic psychotherapy like mirroring can spoil the data of a research interview as the interviewer’s initiatives in meaning making and evaluative negotiations cannot be separated from the interviewee’s point of view any more.

Another danger may arise when the uplifting and appreciative atmosphere may result in certain mild forms of “folie à deux,” for instance when patients and interviewees join in overemphasizing the positive aspects of illness experiences for the sake of each other or for the sake of the internet audience. This may result in preferring stories of successful coping endeavors and the benefits of personal growth in the aftermath of suffering, thus drawing on culturally favored stories.
like the “restitution narrative” (Frank, 1995, 75–96) or the ones celebrating the “redemptive self” described by McAdams (2006). The interviewer must be observant and eventually take care to make room for the expression of sorrow and negative feelings. An empirical indication of this danger may be seen in occurrences many qualitative interviewers know well: that the problem stories indicating critical points, crisis and ambivalence are often told after the recorder has been switched off.

The personal relationship developing in the course of the interviews is backed from the side of the interviewer by his or her roots in the ethics of narrative research and narrative medicine. This must be taken into account when new research programs develop which intend to use the interview data for secondary analysis. Even if this is legitimized by the informed consent procedure, a most important question is whether the research questions are compatible with the trustful exposure of personal and intimate experiences of the patients. When participants have initially been invited with the promise to reconstruct their personal expert stories, new approaches to the data must be scrutinized whether they fulfil this criterion of rendering the patients’ perspectives, or whether they aim at top down categorizations, use pathologizing concepts or evaluate patients’ endeavors with allegedly objective criteria.

What has not been sufficiently explored in this chapter with respect to the special usage of the DIPEx project is the effect of the future internet appearance for the interviewees, as their interviews are partly presented as video, audio or text clips on the website. What it means to be published on the net and to present one’s stories to a vast public may have a very special effect on the course of the interview itself. This can even be shown in the data, as the interviewees often address fellow sufferers, medical professionals or “the public” implicitly or explicitly. This is special to our own project and asks for a new perspective with regard to the internet and its facets of delivering virtual “third spaces,” which may be a promising prospect for future research.

So, in summary we can state that qualitative research interviewing in the medical field should not only be regarded as an act of data collection. It can turn out as a most astonishing enterprise for both partners with lasting consequences and as an important and often profound experience spent together.

References


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