Medicine and the Other: The Issue of Difference in Medical Knowledge and Practice of the 19th and 20th Centuries

Veranstalter: Graduate School „Life Sciences – Life Writing“, University Medicine and University of Mainz; Research Unit of Historical Cultural Sciences, University of Mainz
Datum, Ort: 06.10.2016–07.10.2016, Mainz
Bericht von: Livia Prüll, Institute for the History, Theory and Ethiks of Medicine, University of Mainz; Ylva Söderfeldt, Max Planck Institute for the History of Science, Berlin

This conference, which was carried out as a cooperation between the Graduate School „Life Sciences – Life Writing“ (University Medicine and University of Mainz) and the Research Unit of Historical Cultural Sciences (University of Mainz) dealt with the historical relationship between medical expertise and people marked as „others“. What – at first glance – appeared to be an ordinary idea, developed to a difficult undertaking. Not everybody who arrives at the hospital needed and needs to be a „patient“. And individuals belonging to specific „other“ groups, who are contacting representatives of medicine, do not self-evidently see themselves in strict contrast to those persons who can be called „normal“. Moreover, many „other“ persons have the wish to be „accepted“ by their environment, try to settle themselves within society, at times setting up a „parallel world“ with numerous interactions and collaborations within and outside of their community.

The introduction by YLVA SÖDERFELDT (Berlin) and LIVIA PRÜLL (Mainz) gave background information on the origins and specific issues of the meeting. One of the first explanatory tools was distancing from classical „patient history“. Starting in the 1980s and above all in the 1990s, „the patient“ often was taken as a representative of the social in social history of medicine, and thought of in terms of an „ordinary person“. The typical narrative was about how physicians struggled with their patients, and with other actors, for the power of interpreting health and disease. In contrast, the task of the conference was outlined as the question: How have *extra-ordinary* people regarded health and sickness, and what significance have health and sickness had in the shaping of various *extra-ordinary* experiences and assignments of *extra-ordinary* roles? Of course, based on a complex web of ambiguous power relations, of alliances and conflicts, we can say that struggles for self-determination for a wide range of groups at one point or another played out in relation to the medical realm. But even in close chronological, social, and geographical proximity of one another, one group loudly proclaims that they aren’t sick at all, seeking to escape what they describe as the oppressive grasp of medical experts and institutions, and another group fighting for their illness to be recognized, to be allowed to enter that very medical space as patients, setting their hope to medical resources as a road to emancipation. It was possible to differentiate mainly three groups: First, we can make out certain social groups whose members were (and are) carriers of a specific phenomenon, which may or may not have been unanimously agreed upon as being „pathological“, but nevertheless made them in one way or the other reliant on medical experts to lead their lives. The phenomenon in question might be a definable bodily change that shapes the existence of these persons since their birth or a psychological change. On the other hand, there are social groups, where a pathological phenomenon was interfering with their lives to the extent that reinterpretations of the sense of life and life conduct seem to be inevitable.

Another question is why medical help was and is needed among various groups. Often, it was more than only the need to get access to specific substances or other prophylactic or therapeutic measures. The medical intervention was part of an effort to create a „parallel world“, the attempt to create accommodating spaces parallel to (and not against!) the mainstream, allowing them to live according to their own requirements and intentions.

The first section was devoted to regarding the communication of the „others“. MITA BANERJEE (Mainz) addressed the question of „otherness“ in medicine by looking at a dialogue between the neurologist Oliver Sacks and the animal scientist Temple Grandin, who has autism. Sacks opened up a space for

Grandin to describe her own thought processes as a person with autism. This was only possible for Sacks because he suspended his own medical knowledge and diagnostic gaze for the sake of listening to the full complexity of Grandin's narrative. On the other hand, Grandin described her position as someone who is enabled to review the mentality and habits of non-autistic persons as a sort of „anthropologist from Mars". She proceeded to inspect, from the vantage point of a person with autism, the rites and habits of non-autistic society. Banerjee pointed out basic features of transfer between a medical expert and a person marked as „other". Whereas Banerjee concentrated on discussions and talks as a medium of exchange, HORST GRUNER and WIM PEETERS (both Hagen) devoted their analysis to written discourse. Going back into the 19th century, they described how patients with neurasthenia published narratives of their own suffering. Since they reached the „ordinary" reader, their initiative went far beyond the gaze of the medical experts. With their writings, the sufferers from neurasthenia on one hand could promote self-healing and also to strengthen self-esteem. On the other hand, they could develop themselves to authorities regarding the character of their own „otherness". This was done – as Gruner and Peeters could show – on the basis of different stylistic genres. It was a sort of empowerment of the neurasthenia patient since she could make her voice heard on the basis of a symmetric relationship to the reader – which means to the non-neurasthenic contemporary.

The second section was devoted to those, which postulated on one hand to be a „patient" but on the other hand claimed for empowerment to lead their own lives and to configure their own access to the disease. YLVA SÖDERFFELDT (Berlin) in her paper described and analysed the fate of the hay fever patients. These patients organized themselves in a „Hay Fever Federation". Söderfeldt's story is on one hand a story of empowerment, since hay fever patients gathered data, promoted research and educated even physicians. On the other hand it is a story of the succeeding division of knowledge: Since the 1920ties, medical associations on allergology were founded, which developed to be the authority in explaining hay fever. This meant a division of roles: Medical professionals conducted research and the Hay Fever Federation educated the patients.

Whereas Söderfeldt concentrated mainly on the patients, OLIVER FALK (Berlin) in his case study on diabetes therapy, focused the changing attitudes of physicians. Whereas Söderfeldt's hay fever patients unfolded an initiative to improve their own fate via research and communication of results, Falk's empowered diabetic patient was mainly a product of the activities of medical specialists: He argued that the self-confidence and individual freedom of diabetic patients was mainly a product of the philosophy of early diabetologists. Already in the last decades of the 19th century, physicians championed the „intelligent" patient, someone who was supposed to organize her life according to the guidelines of their supervisor. Above all after the introduction of insulin in 1921, the compliance of the patient was postulated as a main issue of treatment.

The paper of KRISTIN BARKER (Albuquerque) ventured again to the patient's view when discussing the medical expertise of Internet users. Barker focused on online forums devoted to fibromyalgia and apparent side-effects of fluoroquinolones, a type of antibiotics. Using the theoretical frame of cybersomatic connectivity she enhanced the scope of the conference when showing the emergence of the internet as a tool for altering the illness experience but also the medical practice as such of respective diseases. Internet – as it seems – goes far beyond the classical self-help literature e.g. of the neurasthenia patients as well as letter exchanges between diabetic patients and diabetologists. This argument is strengthened when looking at other groups of „others", e.g. transident/transsexual persons who could build up a self-help community only via the Internet since the 1990s.

The third session was devoted to those „others", who refuse(d) the idea to be patients, but are equipped with specific morphological traits that made them interesting for medical experts.. ANJA WERNER (Halle) spoke about the negotiations between prelingually deaf people and otolaryngologists.

This relationship was not without tensions since deaf persons did not see themselves as „patients", and saw their condition as a contribution to cultural diversity. In contrast, otolaryngologists supported a medicalized view and normalizing efforts such as oral education. This way, the deaf community was put under significant pressure to give up sign language well into the 1980s.

The story of the deaf and their negotiations with otolaryngologists is a case study of delayed empowerment and long prevalence of medical specialism. The same is true in the case of the largest group stigmatized in society including medicine, namely women. ANITA WOHLMANN (Mainz) presented an analysis of the controversy between 19th century authors Edward Hammond Clarke and Eliza Bisbee Duffey on the biology and societal role of women. The controversy between Clarke, who postulated that women's physical nature forecloses co-education, and Duffey, is remarkable since both used plant metaphors. Duffey used the plurisignifying quality of metaphors as spaces of agency and resistance against misogynist notions. The paper of DANA MAHR (Geneva) added to Wohlmanns paper insofar as it shows the dynamic development of women rights activities until today: Mahr adressed the „Gynopunk Movement", a Spanish feminist health collective committed to on open-source mastery of medical and digital health technologies. They see themselves as pioneers in decolonizing the women's bodies. Mahr showed that the „Gynopunks" had predecessors already in the 1970s. But with the speculum as a sign, the Spanish group took the most recent step of this decolonization, since it developed methods for self-examination of women and invaded the medical sphere.

The fourth and last session dealt with persons, whose psychosocial condition caused them to appeal for medical aid, although they do not see themselves as „patients". LIVIA PRÜLL'S (Mainz) paper was a presentation about „transidentity": persons, who suffer from an incongruence of physical and psychological sex/gender. Prüll used a case study to show the mechanisms necessary to install a „parallel world" of transidentity within society. The British racing ace and fighter pilot Robert(a) Cowell, who underwent gender confirmation at the beginning of the 1950s, was already engaged in networking, and she instrumentalized the media in getting support from her environment. Comparing the period of conservatism and denial of transidentity with the period of multiculturalism after 1990 enables the researcher to detect the necessities of empowerment of these „others": This is more or less an interplay of societal democratization, networking of self-help-groups, the change of the medical gaze as well as negotiations about empowerment.

PER AXELSSON (Umeå) presented a paper on ethnic diversity and the acknowledgement of respective ideas on health and health preservation. His study, carried out with his colleague ANNA-LILL DRUGGE, concentrated on the efforts taken since the 1940s to analyze the spreading of infectious diseases among indigenous people. Western researchers used isolated „primitive" societies to prove the meaning of immunology and defense on the increase of infected patients. Namely the Inupiat in Alaska were used for research purposes, which can be termed as „ecological imperialism". Axelsson pointed out that this agenda has is equivalent in modern trends to set up bio-banking. On the other hand, there are initiatives to empower the Inupiat to develop and organize their own research theories, tools and methods (participatory health research).

In summary, the conference showed that viewing divergent phenomena in society as being „other" means on one hand to cover both the „classical" patient as well as groups seeking medical advice or help without the intention to go through the therapeutic mill of a medical system. On the other hand, especially case studies give access to specific problems of sub-groups of society. On this basis it seems to be possible – although it remains to be a challenge – to elaborate systematic knowledge on parallel world constructions considering the interactions with medicine. The presentations worked out the complexity of this situation, but also the dependence of the empowerment of social groups on the media, the „Zeitgeist", the internal hierarchy within the „other" group and also within the medical sphere, the change of medicine and finally the dependence on discursive channels and styles of communication. Among the participants of the conference it was agreed upon following up the results and planning further research on the subject. The reason is that much remains to be done to arrive at more fundamental insights into the fate and actions of „others“ in society.

Conference Overview:

Introduction: „Others“ in the 19th and 20th Centuries
Livia Prüll (Mainz) / Ylva Söderfeldt (Berlin)

Communications from the „Others“

Mita Banerjee (Mainz): „An Anthropologist from Mars“: Temple Grandin, Oliver Sacks, and Narratives about Autism between Life Sciences and Life Writing

Horst Gruner / Wim Peeters (Hagen): „My Nervousness“. The Autobiographical Case Construction of Otherness Among Peers in Neurosthenia Self-Help Literature around 1900

Becoming a Patient in the 19th and 20th Centuries

Ylva Söderfeldt (Berlin): Knowing and Being Known. The German Hay Fever Federation 1897-1968

Oliver Falk (Berlin): „The most important Part“. The Narrative of the „intelligent Patient“ in Diabetes Therapy (1870-1950)

Kristin Barker (Albuquerque): Who knows: Patient Expertise in the Internet Era

Medicine and Embodied Difference in the 19th and 20th Centuries

Anja Werner (Halle an der Saale): Conflicts of Interests? The Otorhinolanryngologist and the Sign-language-Using Deaf Patient in Historical Perspective

Anita Wohlmann (Mainz): Brain-Uterus Competitions: Renegotiating the Female Body through ‚Medical' Metaphors

Dana Mahr (Geneva): The Speculum of Wonder Women. The long lasting Decolonisation of Women's Bodies in the 1970s and Today

Medicine and Social Identities in the 19th and 20th Centuries

Livia Prüll (Mainz):Transidentity in the 20th Century – The Life of Robert(a) Cowell (1917-2011) as a Case Study

Per Axelsson / Anna-Lill Drugge (Umeå): From Virgin Soil Epidemics to Participatory Health Research – Western Medicine and Indigenous Research

Tagungsbericht *Medicine and the Other: The Issue of Difference in Medical Knowledge and Practice of the 19th and 20th Centuries*. 06.10.2016–07.10.2016, Mainz, in: H-Soz-Kult 08.12.2016.