

FILE NAME: (Public Roundtable Voices and Ethics Part Two with Alfred Hornung)

Speaker Key:

AH Alfred Hornung

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AH Okay. My topic is concerned with teamwork across the disciplines and also maybe if we talk about ethical issues. The idea how we can finance students doing research in a group of scholars and postgraduate studies. We have been doing for a long time life writing at the University in Mainz and all of a sudden three years ago we had a sponsor, a pharmaceutical company called Boehringer Ingelheim which gave 100m Euros in order to establish an institute for molecular science and molecular biology or life sciences. The State then contributed 40m Euros in order to build the huge building and every time I drove on campus I thought this is where the money is, you know, and thought about a combination of life sciences and life writing and we eventually managed to make an application to the Trans Bridge [s.l. 01:18] Foundation in order to get what is called the research training group which potentially funds a group of doctoral colleges over a nine year period which allows three cohorts of 12 graduate students to gain a PhD or a MD Degree. That was the point and the name of this project is called Life Sciences, Life Writing, Experiences of the Boundary of Human Life between Biomedical Explanation and Lived Experience. Each of the candidates who is funded for a three year period with a monthly stipend of 1,200 or 1,500 Euros depending on the marital status. There's also funding for a coordinator. The 12 colleagues who are the principle investigators and direct the dissertations usually in a combination of life writing and life science expertise.

Then we have additional expertise which comes from a group of 19 national and international associate members. We're affiliated and I invited for lectures or short-term visits and we also cooperate with autobiography standards such as the one here and on a global scale. The format of the research training requires an offer of a number of courses in which the foundations of the research are discussed, but the major part is the writing of the thesis hopefully in three years.

The first cohort of 12 students throughout Germany, Canada and China started last year in April and we hope that they will finish two years from now and potentially this whole programme was about two million euros over this nine year period. Now I'm going to talk about the way in which we set up the programme as a cross disciplinary research in life science and life writing and I will then present three projects that students are working on in medical studies, pharmaceutical studies and life writing using the descriptions which the students present. Now the programme, the research and training programme of the

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Graduate College aims at establishing mutually shared methodological pathways to topics in life sciences and life writing related to boundary experiences of human life. The Graduate College proceeds from the hypothesis that in the explanations of boundary situations of human life, life sciences and biomedicine on the one hand and the humanities cultural science on the other hand. Approach to the same stuff like of humans in their life world from different angles. In the sense life sciences and life writing can each be understood as a specific set of narrative practices in which the significance of explanations and models depend to a large degree on the ways in which empirical data explanation and experiences are narrativised.

From the 20th Century to the 21st Century the conditions of human life have changed dramatically due to political, socioeconomic, ecological and cultural influences. Simultaneously the interpretive models and spaces of action in medicine have shifted from observing and influencing biological processes towards the biological and technological shaping of health and disease. Examples are many fold. Assisted reproduction, pre-natal diagnostics, organ transplantation, longevity and dying. In all of these boundary experiences the role of medicine has changed fundamentally and has influenced the ways in which we conceptualise and deal with human life. These develops have also resulted in new approaches to explaining and understanding human life and life narratives and social and cultural studies. Over the past few years life writing has widened its scope in terms of content of method to include all areas of life, all forms of this presentation, in all media and over the past two days we heard a lot of that and maybe in continuation of the programme we have to have online the media, but that is a different story.

The graduate programme converges areas of life sciences and life writing and sees them as complimentary approaches to understand, explain and act in boundary experiences of human life, to achieve this conversation joint concept need to be established. So we focus on three research areas. Corporality, ability and temporality which function as three conceptual spaces within which biomedical explanations, literary and cultural analysis and human experiences interact. Corporality refers to the materiality of the human body but not only its biological part but also the investment of cultural expectations, values and requirements.

The second category, the ability looks at the loss or gain of the body and mind. Received in boundary situations but the need of the biomedical disciplines for systems of orientation beyond diagnostic tables. The third category of temporality departs from the basic fact of the human being as a temporal being subject to chronological and biological time. In many boundary situations such as trauma, post-traumatic situations or chronic diseases which last for life the aspect of temporality becomes crucial. Based on the assumption that these three categories of corporality, ability and temporality are intermittently related to narrative practices with postulate for the research programmes approaches. Narrativity and narratability, the conceptualisation of narrative practices. The materiality of narration and

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if we also look at objects that tell stories. Narrative transformation. Narration as an epistemic project and different aspect of a narrative cell.

The interdisciplinary approaches are linked by narrative practices which function as a conceptual and methodological background against which boundary situations and experience of human life are studied from diverse disciplinary angles, such as medicine, neonatology, psychotherapy, pharmaceutical biology, molecular biology, social sciences, cultural anthropology, history, philosophy, ethics, transnational cultural studies and ecology.

I now would like to look at three and shortly talk about some of the projects that students have started to work on for their doctoral thesis. The first one is by Miriam Hollstein was a project on pre-term birth. A qualitative interview based study about the experiences of parents. I mean, several projects among the 12 in which deal with childbirth and child trauma so that they're inter-related in the other group. Though sadly any other medical specialty where the limits of what is considered to be medically possible but also ethically preferable is changing as quickly as neonatology. When a child is born pre-term in this rapidly fluctuating environment that is so highly medically engineered many parents describe the situation as a liminal experience because of the intensity and gravity of the situation. As parents they have custody and therefore they have to make decisions concerning the child's health and the nature of prognostic uncertainties. Most of these decisions touch the border of liability and distinct limits have been constantly stretched and blurred through medical progress. The statistics and data that usually provides some comfort of time, of evidence based medicine do not represent a safe basis of decision making in neonatology.

In clinical studies the number of medical cases is constitutionally small and the particular case history is often too individual to be easily and safely classified. Additionally in most cases it is hard to properly judge the extent of the child's impairment for the age of six or seven. Furthermore the clinical practice of neonatology could drastically change within a period of six to seven years, so that the time the research results are published the guidance they provide is very limited. This research project the student will explore the liminal experiences of parents whose pre-term born children spent the first week of their life in the neonatal intensive care setting. The parent's narrations in these qualitative interviews will provide extensive and complex insights into their liminal experiences.

The interviews will be conducted with parents of children of three different age groups. Parents of one or two year old. Parents of a six to seven year old and parents of a child who was born in the 80s and who is already a young adult, so it stretches out. The analysis of these qualitative interviews will focus on the narratability of the event as well as the epistemic meeting place. I will be explored but what kind of appearance that the parents speak which are narratable and about which they cannot narrate. It will be discussed what kind of

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influencing factors help to narrate an event more easily and to what extent are the context of narrating, shaping the narratability of an event. In order to cope with pre-term birth it might be necessary for the parents to renarrate this liminal experience with the help of one personal surroundings and friends until their life story can be told as coherent. The process of co-narration might be impaired if there's no epistemic meeting planned.

Actually the Director of this paediatric clinic who also gave a report and is one of the principle investigators about children that are not born yet. You know, that might be born after 24 months of pregnancy and then the decision between the parents, the doctor about the child that is still in the womb creates stories and also subject of analysis.

The second project that Laura Schneider [s.l.13:10] writes on, experimental subject in clinical pharmaceutical research. This is a project about the need for biomedical innovation to find experimental subjects in pharmaceutical research. The process of offshoring clinical trials to Eastern Europe, China, India where recruitment of possible research subject is said to be much more effective than, for example, in the US and some Western European countries can count as one reaction to the challenge. In the wake of such phenomena anthropologists and social sciences mainly sit in the US, Australia and Great Britain. It started to focus their research on the clinical trials industry. Inevitably touching the problem of the experimental subject and a theoretically empirically informed basis. Despite the fact that global varieties of capitalism also clearly have an effect on research in drugs. Little is known about the social structure of those who provide the bodily functions for research, about the experiences and their way to make sense of participation.

Whilst the academic debates around experimentally subjects it's often narrowed down to ethical guidelines under the imperative or protection. This PhD project aims to shed light on those marked potentially vulnerable persons who are willing to face the double liminal experience between being merely human experimental grounds and personal integrity between experimental medicine and bodily intactness from a social scientific perspective and let them speak.

The final topic is by Ruth Steinberg, a literature person on dystopia and fiction. Her project deals with the representation of bio-ethical borderline situations in dystopia and literature. Dystopia and fiction represents an interesting feel for life writing since it focuses on the individual in borderline situations and engages with personal reflections of lived experience. [Inaudible 15:30] draws attention to the ethical dimension of present day decisions by highlighting the future implications and the effect on the individual in a most extreme form. By focusing on fictitious literature not only the aspect of what currently is, but also what could be will be incorporated in the portrayal of lived experiences. The student implies that cultural, ecological analysis which will allow her to perceive dystopia, not just as a distorted version of the present but to emphasize intricate establishment of counter-discords and to integrate them into the current interdisciplinary discussion.

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What can we draw as a conclusion for this project of life science and life writing cooperating with these 12 students, 12 principle investigators and a team of affiliate members? I think a common basis of our research is a definition of life. Life proceeds life writing quite obviously. When does life begin? When does it end? How does it unroll in time and space? The focus on boundary situation essentially these questions and particularly ethical questions. These definitions of aspects on faces of life influence, of course, the writing of a life and its observation in scientific terms. Its narrativisation or medical explanation. The radical disciplinary approach between the humanities, social sciences and life sciences will provide much perspective for the discussion of both life and writing and will incorporate new data. It will also foster and force people to work as a team collectively across the disciplines. Finally, the research has also meant to lead to a better communication between medical doctors and their patients. The stories or the kind of reports that patients receive from the medical doctors usually are not in such a way that patients understand them and this is also a project that is connected with this research. These hopes coincide with effort pursued in the medical humanity such as here at King's College or the narrative medicine programme run by Rita Charon and Laura Spiegle [s.l. 18:06] Columbia University. Thank you.