

Workshop 33

Facing Distress. Distance and Proximity in Times of Illness

Convenors:

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Distance and proximity are concepts par excellence to describe what may happen in times of illness and suffering. The possibility of proximity of the sick person and others manifests itself, but the opposite will also happen resulting in loneliness and feelings of desolation. Nature and quality of social relationships can be caught in times of illness and suffering. Illness raises questions for all individuals who are involved in the process concerning the relationships between individuals and between individuals and society. In times of illness, the sick individual will question his/ her relationship with others and being-in-the-world. In relationship with others, such as doctors, a sick person can experience empathy and compassion, but also conflict and struggle. Another example of distance and proximity is the difference between the work of anthropologists and doctors. This difference focuses the attention to the relation between empathy and the production of knowledge.

Issues of distance and proximity in illness and suffering can be found in various situations; distance and proximity are related to age, gender, kinds of illnesses and they depend on the anthropological approach.

Ethnology and Medicine: Empathy, Experience and Knowledge

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If the issue of empathy is largely debated in disciplines such as ethnology and medicine, however, the relation of the ethnologist to his informants is not at all identifiable to the relation of the doctor to his patients, and the empathic dimension, considered to characterize them, is not the same in both cases. I will start from examples drawn from various fieldworks in order to examine, in a transverse way, the nature and the place of empathy in the contexts of the medical relationship and the ethnological relationship, and to try to evaluate the part it plays with reference to knowledge, which these two types of relationships aim at. What are the implications of empathy on the work of the medical doctor and on that of the ethnologist, and what is its heuristic value? In other words, which bonds does empathy have with the process of knowledge? It will be shown that if, in these two types of situation, empathy may be useful, the benefit which the ethnologist can draw from it, is such only if he, unlike the doctor,

succeeds in distancing from it and in controlling it.

Distance and Proximity in Refugee Medicine

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With the professionalisation of psychiatry, issues of culture, justice, and politics are preferably kept at a distance in by psychiatrists. For refugees who turn to psychiatry for help, however, these issues are often the most proximate ones in their minds and souls. Particularly asylum seekers confront psychiatrists with the limitations of their professionalism, which may ultimately result in a denial of access to care for this group of patients. In therapy rooms where psychiatrists and asylum seekers do meet, border fights between both parties and negotiation processes within the minds of each party are a regular occurrence. A psychiatrist has to negotiate with him- or herself as empathic human being and as professional transforming suffering in distanced categories of disease, as critically engaged citizen and as representative of the state. An asylum seeker has to negotiate within him or herself between silencing and disclosure, between faking illness and indicting injustice. These negotiation processes have repercussions on the border fights between psychiatrists and asylum seekers, in which a variety of positions of distance and proximity between both parties can be identified.

Feeling, Distance and Emotions in Medical Practice

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The paper aim is to show the rhetoric produced by doctors on doctor patient-relationships and the contradictions inside the hegemonic models in clinical practice between the need of distance: represented by clinical examination and the implication of the professionals in the management of pain and sentiments. The paper tries to show the complexity of the question exploring different medical settings in today medical practice and in the past, and the medical rhetoric about positivistic strategies to gather signs and symptoms and to develop diagnostic tools.

Parents' Relations with Prematurely Born Infants: Distance or Devotion?

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Parents of prematurely born infants often experience repeated periods of distress due to the infant's life-threatening situation and the possibility of future impairment. In the paper, parental experiences of proximity and distance to infants born with extremely low birth weight will be in focus. It is based on fieldwork in a neonatal intensive care unit in Iceland, and interviews with parents of infants with birth weight 1000 g or less born

September 1998 to August 2002. I present parents' experience of the birth, their first encounter with the child, and involvement in his/ her care in the hospital and at home. I discuss urgent baptism and parental concerns to choose an appropriate name to the circumstance of birth and reactions to reluctance of family members and friends to give birth presents. Particular attention will be paid to different experience of mothers and fathers, e.g., fathers often see their child before the mother, and the life of the mother and infant may be in danger. Finally, the results will be discussed in the light of theories concerned with parental reactions to unviable births.

Crisis of Proximity in Medical Anthropology of Suffering

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The authors explore distance and proximity towards older people from the perspective of reciprocity. They have done anthropological research among older people in the Netherlands, South Africa and Ghana. The Dutch study suggests that older people feel 'unsuccessful' if something fundamental is missing in their social contacts. Physical and cognitive decline are a nuisance but 'normal' if one grows older. Old people cannot be blamed for it. Being deserted by children, other relatives and friends is however experienced as personal failure. The Ghana study shows that older people are sure that they will receive material and emotional support from their children and others if they have 'invested' in them during their vital years. The South African study shows that reciprocity between older people and others is shaped by political and economic conditions. Older people often receive no emotional or material support from their children and other relatives. However different the three societies, people in the three studies underscore the decisive role of long-term reciprocity ('general reciprocity'). This paper critically examines this 'explanation' of successful ageing. It is suggested that longterm reciprocity is no absolute guarantee for the maintenance of social contacts. Both in the Dutch and the Ghanaian study good social contacts appear to be the outcome of a mix of long- and short-term reciprocity, while in South Africa external conditions shape the social contact of older people. If conversations and meetings with older people lose their direct reciprocal dynamics (in other terms: if they become unsatisfactory, boring) due to physical, cognitive or economic limitations of the older person, the latter risks to become lonely, without 'deserving' it (i.e. in spite of his/ her social investments in the past). In such a situation life seems to end unfairly, or, to use Cicero's terms, life looks like a play with a sloppily written end.

Working Towards Proximity

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I do research in a forensic psychiatric locked ward in Denmark where I study the interplay between staff and patients from an interactionist perspective.

In this ward nurses work reflectively and professionally with the terms distance and proximity. The struggle to create proximity with forensic patients who very often do not want the proximity is a basic characteristic for the nurses' work.

For this paper I wish to investigate the way small bits of everyday interaction and activity is reflectively constructed as steps along the itinerary towards proximity. I wish to show the negotiation between patients and staff involved in the process, and I wish to show the impact of the field constellation in which it all takes place.

In addition, I wish to compare the proximity-creating work of the nurses with that of the anthropologist in the same field. As I see it, the paths nurses and anthropologists take to create proximity are very alike. Thereby we may as anthropologists learn about our own methods by looking at the nurses' occupation. However, the purpose of the proximity-creating work of anthropologists and nurses differs in important ways as regards knowledge production, empathy and responsibility. At the end of the paper I wish to discuss the impact this difference has.

Witchcraft and the Hand of the Healer. Images of Distance and Proximity

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Illness and suffering in Africa are not only individual issues but are also of concern to the social group as a whole. Perceived as an image, individual illness triggers waves in the social fabric. From a personal point of view illness is experienced as something very close and individual, the patient is confronted with pain and suffering, he might feel disheartened, lonely and lost. From a more distant point of view the patient and his relatives and friends might see this illness as a social phenomenon, which manifests itself in accusations involving witchcraft or other concepts of human agency. Consequently therapy is also embedded in these perceptions of proximity (individual suffering) and distance (witchcraft). The healer treats the patient with his hands (in German "behandeln"), massages painful muscles, holds aching heads and gives the patient medicine. He takes care of his bodily ailments and comforts him. The hand of the healer represents closeness and is therefore the most prominent healing symbol. The distant aspect of illness and suffering as reflected in witchcraft requires the intervention of the social group. Witchcraft is a feared threat that disturbs the social fabric, but it can also act as a regulator when social conventions are violated. Illness and suffering are expressions that something has gone awry on an

individual and social level.

Adapting to Mobility-Disability in Older Age

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This paper examines older people's descriptions of mobility disability in the UK, primarily that which is caused by arthritis and stroke. Older people's own representations of older age and physicality show how their experiences of increased mobility problems are intertwined with their experiences of social relationships with partners, family, friends and health service providers. This paper explores how older people describe these relationships and examines how increasing stasis and thereby proximity to "home" does not necessarily mean distancing from others or the world. This said, older people's relationships with others do alter their form at critical points such as time of diagnosis, or at critical events such as falls. Well-being, adaptation and acceptance of some degree of mobility-disability in older age may hinge of how these relationships reconfigure at these times. This work reminds us that trajectories of disablement in older age are fluid and punctuated, and how the minutiae of relationships with others may influence how people experience those trajectories.