

Human rights violations against people with mental illness, epilepsy and disability

Amnesty International's Action Network for Health Professions organizes international symposium in Kassel

On 16.02.2019 a symposium on human rights violations against people with mental illness, epilepsy and mental disability took place in the Gießhaus of the University of Kassel. The conference was organized by Aktionsnetz Heilberufe, financed by Amnesty International and simultaneously translated into two languages (English and German). Members of Amnesty International, representatives of NGOs and other interested parties were present, many from therapeutic professions.

La maladie du demon - disease of demons

On the evening before the conference, director Lilith Kugler took the audience to Burkina Faso with her award-winning debut work and presented the situation of people with mental or epileptic diseases. People suffering from psychosis are hidden in sheds for their own protection and that of the community and are tied to trees there or in nature. In some cases, prayer camps are used which are located far outside the community, are only known in the immediate vicinity and are not subject to any controls. There they are provided with food by their relatives or, if they do not visit them, by members of the camp. The "treatment" usually takes place exclusively with prayers in order to expel the evil spirits. There is no psychiatric supply of medication. The sick often spend years under a tree and the film shows an example of a person digging deeper and deeper into the earth and others talking to themselves or even silencing completely. Sensitively and without any pathos, Lilith Kugler, accompanied by a parish priest, Guitanga Tankpari, presents the situation and the background for the experience and action of the local people. The pastor visits some patients and tries to free them from their chains and to find a place for them in their communities again. The Christian pastor tries to combine the traditional culture with human accompaniment and the achievements of medicine in order to bring people back to community and recovery. Medical care is provided by a psychiatric nurse, Timothée Tindano, who travels from far away and has an outpatient consultation two days a month. The supply of medication is a major problem.

Also affected persons and the consequences of the illness for them and their families are presented. The situation of the helpers in the local aid project is also addressed. The diseases are interpreted in the local tradition as an expression of obsession, which leads to the fact that the demons must be driven out or tamed. The demons can also jump over to other people and so the helpers are sometimes also suspected of being infected by the demons. But the film also shows how elementary care can be developed with simple means. This care is currently being expanded with the help of two German NGOs.

The director was present during the following discussion and answered the numerous questions. Meanwhile she is back in Burkina Faso, showing her film there - also to the people who participate in the film - and she and we are looking forward to the resonance there. The film can be requested for screenings in cinemas and events in order to reach a broader public for the topic in other countries as well.

Amnesty International's Position on Mental Health and Human Rights. Starting point and questions

Michael Huppertz, psychiatrist, psychotherapist, sociologist and member of the Aktionsnetz Heilberufe, introduced in his introductory lecture the topic of long hidden human rights violations against people with mental and epileptic diseases in countries without relevant psychiatric care. He spoke from a human rights perspective about the problems that arise on the way to improving their situation. If in the past decades there was protest against abuse of mentally ill people, it was in connection with criticism of arbitrary and violent treatment within psychiatric institutions. But many more people outside psychiatric institutions than within them are deprived of their basic rights. This is simply due to the fact that there are around 1.5 million beds in psychiatric institutions worldwide, including homes, but at least 200 times as many severely mentally ill people in poor countries who have no access to psychiatric treatment. It is only since about 10 years that the problem, which has been known to experts for a long time, has been brought to the public by investigative journalists. Human rights organizations, including Amnesty International, have also paid little attention to the situation of this large part of the population to this day. So it is also about an inclusion of this group in the human rights movement. Using the development of Amnesty International as an example, he explained how the organization initially devoted itself to political prisoners and civil and political rights, and later on generally campaigned for the abolition of torture and the death penalty. In 2001, the mandate was extended to the protection of all human rights.

Sometimes, but never comprehensively, the situation of mentally ill and disabled people was taken into account. Recently, however, the issue seems to be gaining more attention at the international level, which has been promoted by important international conventions. Various problems have arisen with regard to cooperation with regional and state actors, the plausibility of the modern concept of human rights in rural regions, the possibilities of NGOs to influence international negotiations and national health policy. Especially NGOs that are practically active on the ground have to bear in mind that they do not contribute to the mistakes of Western psychiatry being repeated in the development of psychiatric care in developing countries. In particular, the establishment of large, separate psychiatric institutions should be rejected because it is inefficient and expensive and because such institutions are particularly vulnerable to human rights violations under precarious conditions. In addition, there is a danger that the governments of the countries concerned, which generally spend very little or nothing on mental health, will be relieved of responsibility for the issue of mental health. In the efficient and affordable development of psychiatric care within general decentralized and outpatient health care, on the other hand, one can refer to the international expertise of the WHO, for example. At the end, Michael Huppertz formulated numerous questions for the participants of the conference, the answers to which could be important for a possible future engagement of Amnesty International.

Global mental health and human rights - an overview of the current situation

Wolfgang Krahl of the International Network for Development Cooperation in the Field of Mental Health e.V., psychiatrist and forensic scientist, who has been active for decades in various emerging and developing countries in research, education and cooperation projects, impressively demonstrated, based on the Declaration of Human Rights, that mental health has long been neglected in the realization of these human rights. Families, especially in poor countries, are the only supporters of mentally ill people who, for their own protection and that of others, resort to numerous human rights violations, for example by chaining their relatives to chains and locking them away. The best anti-Stigmaprogramm is a good treatment and rehabilitation! It also takes the burden off the

affected families, relieves them for other tasks and activities and is a concrete development aid. According to the WHO's catalogue of objectives, this includes good initial care for mentally ill people right into the local communities, the provision of psychotropic drugs, the training of mental health experts, who do not have to be psychiatrists, and then also educational work and psychoeducation. This requires state implementation and networking of various sectors, monitoring and further research. He pointed out that in Europe, too, the development of psychiatry was a long process that began in the 18th century and led to the first liberations of the mentally ill from their shackles. Wolfgang Krahl also recalled the most comprehensive and organized human rights violations in Germany between 1933-1945. Within the framework of the T4 program, 200,000 sick people were systematically murdered, many of them forcibly sterilized, with the significant participation of psychiatrists and nursing staff.

Wolfgang Krahl presented how much money states spend on psychiatric care and how the gap between countries with high and low per capita incomes diverges. Low and lower middle income countries usually spend less than 1% of their low health budgets, sometimes nothing at all, on the treatment of these diseases. As a result, billions of people would have no access to psychiatric care. After infectious diseases and injuries, mental illnesses are the most common diseases. He showed what drastic consequences this can have for those affected. As a rule, traditional healers are the first port of call for those affected and their families. Traditional healing methods could also be sometimes successful for mild forms of depression, dependency diseases and neurotic symptoms. In the case of severe depression, schizophrenia, bipolar psychoses and epilepsy, on the other hand, psychiatric treatments, including psychotropic drugs and antiepileptic drugs, would have to be used not too late.

Mental health and human rights in Côte d'Ivoire

Nathalie Kouakou from Amnesty International Côte d'Ivoire spoke about the situation in her country, where she has been campaigning for several years for the implementation of human rights standards in the health system. Especially mentally ill people are impaired in the perception and defence of their rights and are therefore particularly predestined to become victims of human rights violations. Although the WHO defines the right to mental health as a central component of well-being, those affected by mental illness, epilepsy or reduced intelligence are still often stigmatised, excluded from education, political debates, elections, starting a family, etc. The WHO also defines the right to mental health as a central element of well-being. In Côte d'Ivoire, the whole issue of the life situation of the mentally ill is marginalised.

Nathalie Kouakou presented the UN Convention on the Rights of Persons with Disabilities and the Mental Health Action Plan, which call for social improvements for people affected beyond medical treatment and aim to break down barriers to integration. They want to draw the attention of those responsible and decision-makers, encourage them and point out ways in which they can help to implement appropriate guidelines and protect and guarantee the rights of those affected. In particular, however, the Convention aims at the housing, living and treatment situation, the standards of which must meet today's increased knowledge. A different picture of mental illness should also be brought into society, for example through improved education of the population. Degrading treatment and accommodation should also be punished, as it should be possible for those affected to complain about it. The government should provide instruments to strengthen patients and their families, for example in the form of associations and self-help groups. Large psychiatric institutions in large cities should be replaced by psychosocial and medical care closer to home. In order to guarantee all of this, government offices for coordination and planning would have to be created in the administration. The African Union had also largely joined the postulates of the WHO, but there was still a lack of visibility of the problem in the country and a lack of commitment on the part of the

Ministry of Health. The precarious situation of the lacking resources on the one hand and the little committed approach to the implementation of the guidelines on the other hand promotes the continuation of the traditional practices of the religious-cultural understanding of mental impairments with the danger of the continued mistreatment, disregard and exclusion of the affected persons. This also includes sexual abuse within the framework of magical thinking as well as kidnappings and the removal of organs.

Despite the otherwise dynamic process in the development of the country, the magical thinking of guilt, magic and obsession prevails here. In addition to the already weak medical care in the country, which was still affected by the military coup of 1999, various crises and the civil war of 2002-2011, there is an increased incidence of trauma disorder. Psychiatric care is scarce, and only 25% of health districts have any form of psychiatric care at all. On the other hand, Côte d'Ivoire has a new constitution in 2016 which stipulates that all people with disabilities must be protected from discrimination and that no one must be disadvantaged because of their mental or physical condition.

In her concluding demands, Nathalie Kouakou underlined the need for further research into the epidemiology, sociological data and legal status of the diseases in question in Côte d'Ivoire, improved accessibility of the initial contact points in the municipalities, also for mental illnesses, for investment in training for specialist staff, but also for volunteers in the village structures, in order to build up a good support network and educational work.

From West Africa to Southeast Asia: Transforming access to mental health care through WHO Quality Rights and CBM's mental health work

Carmen Valle works as a consultant for mental health projects of the Christoffel-Blinden-Mission (cbm), in particular with regard to human rights education, in various countries in Africa and Asia. She followed her organization's experience and solution models. She described how it can be possible to create basic networks on the ground, to support decision-makers and people in the care of people with disabilities. Cbm relies among other things on so-called peer groups, i.e. on people who are experienced in life and enjoy the respect of the community and at the same time are open-minded for the implementation of social psychiatric care in the communities and often have a practical therapeutic effect. She impressively presented a well thought-out concept at the various levels of how the countries could continue to maintain and develop the system independently without the support of NGOs. Mental health care and consideration of the situation of mentally ill, stigmatized people with epilepsy and mental impairment should be integrated into the overall concept of development work, for example in educational projects in schools and kindergartens. The idea of inclusion can also be introduced at an early stage here, as well as at parent and community meetings. This also strengthens awareness of the particular vulnerability of those affected to assault and abuse and thus social control, which can serve as protection. The concept of their organization is to provide emergency aid in threshold and developing countries, for example after earthquakes, tsunamis, etc., in addition to the so-called basic needs, and to focus separately on mental health and local work. Worldwide, on-the-spot trainers are trained in first aid for first aid after traumatization according to WHO guidelines.

The situation of traumatized people in Liberia

Susanne Grosse, social scientist at the University of Kassel, as hostess of the event in the Gießhaus of the University of Kassel not only ensured a pleasant conference atmosphere, but in view of her forthcoming research stay in Liberia she not only reported on the similarly disastrous situation of

those affected there with vivid film and pictorial material, but also made it clear on the basis of the standards of care in Germany that we ourselves have not been far away from poor care for so long. The psychiatric enquiries and visitor commissions had provided for more transparency and standards, but needed constant improvement. It is precisely the people affected who find it difficult to stand up for their rights. In projects in Liberia, people are trained for psychosocial support, especially for the numerous traumatized people in the country. Thousands of former recruited child soldiers have now grown up and have families of their own, but often carry trauma sequel disorders with them - with serious consequences for themselves and society.

The practical significance of international human rights conventions for the development of psychiatric care

Margret Osterfeld, retired psychiatrist and committed to Aktion Psychisch Kranke e.V., was not only a committed critic at previous lectures, but also spoke about her work at the UN Subcommittee on the Prevention of Torture, in the framework of which teams regularly visit care institutions in various countries and draw up reports on the extent to which corresponding standards of care are observed or disregarded and improved. These teams usually have access to all mental health facilities and prepare reports on the human rights situation in these facilities. If they do not get free access, they stop working. The reports are forwarded to the competent authorities and proposals are made to improve the situation. A publication beyond that is aimed at, but the organization renounces it, if the addressed governments do not agree, in order not to endanger the further co-operation.

Discussion on the podium and with the audience

The lectures - moderated by Mirjam Ibold, psychologist and member of the Action Network of Health Professionals - were accompanied by lively discussions for which there was plenty of time. The concluding panel discussion - moderated by Gesine Heetderks, psychiatrist and neurologist - focused on the question of what the consequences would be for the possible involvement of Amnesty International. There was a consensus that a dual strategy would make sense for improving the situation of people with mental illness and epilepsy. On the one hand, a sustainable change in their situation can only be achieved if appropriate influence is exerted on the government. The states concerned have signed various conventions of human rights significance, including the important Convention on the Rights of Persons with Disabilities of 2008. They can and must be made aware that the situation of these people is a violation of elementary human rights. On the other hand, however, human rights violations such as chaining people are generally not the result of sadistic motives, but rather of a lack of alternatives and helplessness in dealing with the mysterious diseases. Therefore, such a political strategy can only be successful if it is accompanied by suitable pilot projects demonstrating that in poor countries such as Burkina Faso, Côte d'Ivoire or Ethiopia, medical care for these people is also possible at affordable costs and can therefore be incorporated into government health programs. So it is not a question of pillorying governments, but of using such pilot projects to persuade them to cooperate, in their own interest, because in this way a fundamental human rights problem in their countries can be tackled and perhaps resolved.

It is a question of promoting an encouraging and helpful approach to these people through education about mental illness, epilepsy and mental disability and, above all, through real improvements in the treatment and care of those affected. This information and encouragement should involve those affected and their families, the health workers, but also the authorities and civil society. The motto "Don't blame" should be taken into account as far as possible. Comments should be face-saving and realistic for the responsible governments, so that further investigations, development reviews, new proposals etc. can be made in constant cooperation with the administrations.

Gudrun Brünner