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Discrimination of diabetics in Hungary

When I got the opportunity to explore a topic on my own, I started thinking and in a few moments I knew that I would like to conduct a research on a recent Hungarian decree of analogue insulin therapy. I am generally interested in "applied anthropology" and ethnographies that relate to current issues. I think I chose this topic as I myself have epilepsy, which is an illness often met with discrimination and my mother, who is a diabetologist, told me a lot about this decree. I carried out my research in Hungary during the spring break, interviewing five diabetic adults of different ages, who are somehow affected by the new regulations. I looked for volunteers on the Internet and they applied to anonymously share their views (thus, I use pseudonyms in the essay). When it was feasible and appropriate I recorded the conversations, but primarily I made lots of notes. Firstly, I will give a brief introduction to diabetes and the decree, then I will write about the reception, target and consequences of the regulation. Finally I will be moving on to my focus, which is the possible discrimination and changes in the patients' character formation as consequences of the decree.

Behind the scenes

Diabetes is an illness which affects such a large number of people all around the world that now it is often referred to as a global epidemic. This disease is usually categorized to be of Type 1 or Type 2. The former one is caused by the body not producing any insulin. In Type 2 diabetes the body cannot produce enough insulin or the cells cannot perceive it properly. Diabetics are treated in various ways, which could include diet, exercise, oral medication, insulin pump, even modern therapies like the transplantation of islet cells, however the majority of the diabetics uses human or analogue insulin therapy. Human insulin is less frequently applied as it requires a very strict and systematic lifestyle from its users - even the exact time slots for eating, injections and measuring blood glucose level are determined. On the other hand analogue insulin is a more developed type of insulin therapy. It is altered to have more desirable characteristics than normal insulin, hence, it allows a significantly more flexible life for its users. The latter one is much more expensive. Blood glucose levels show the actual glucose concentration in the blood, while HbA1c levels, in theory, indicate "long-term" or "average" blood glucose levels of the previous months. Although higher HbA1c levels can be indicators of mistakes in dieting or an inactive lifestyle, it can be the result of several other conditions. These may include stress, puberty, any kind of infection or illness with fever, menstruation, use of certain medicines (antiphlogistics; chemotherapy etc.), genetic predisposition or even a weather change. There was even a scandal (Origo) about a woman who had her HbA1c level tested twice in one week in two different laboratories, and there was a significant 1.5% difference between the two results. It was an especially unpleasant situation as one result was under, while the other one was over the 8% limit that the new decree defined to be the threshold. Doctors could not find a rational explanation for the difference, so HbA1c level cannot be very accurately measured, which makes its monitoring usage questionable.

The new decree specifies the monitoring of HbA1c level and its acceptable level. (Doctors usually propose that HbA1c levels should be under 7%, although there are numerous complications in every case, so they like to make personalized recommendations for each person.) The decree (Portal of the Government) says that every year patients are required to test their HbA1c level four times. If the last two values are under 8%, then the patient receives the recommendation from his/her doctor for half a year. This recommendation provides 100% financial support for analogue insulin. If even one value happens to be equal to or over 8%, the patient is entitled to only 50% financial support for analogue insulin for one year, independently from his/her next four HbA1c levels. Paying 50% of the required analogue insulin costs around 5,000-15,000 Ft (~15-45 pounds) monthly, based on my informants. Considering that an average Hungarian wage was 144,040 Ft (~412 pounds) in 2012, according to the Central Office of Statistics, the amount of the contribution one may have to make seems considerable. The decree makes an exception with those who had severe hypoglycaemia and it is documented officially (for example by the ambulance). Those who choose not to pay 50% for their analogue insulin treatment can change to human insulin, which is still 100% financially supported by the state.

Reception of the decree

After discussing preparatory topics, I decided to straightforwardly ask the opinion of my informants about the new decree. Their answers seem to show a similar pattern, which could be the result of their active resistant attitude towards the question. Presumably they were more eager to share their views as their voices could hardly be heard in the state-society discourse. All of them opposed the decree, with minor differences in their justifications. Some claimed that it was 'unfair, outrageous and pointless', while others seemed more disappointed. There was a general consensus that the 'decree could not be practicable, since politicians had made it up, who are incompetent without a real discussion with doctors'. One found it even 'contra productive', because of the long-term expenses the National Health Treasury would eventually have to pay for the treatments that would be required as a result of the less modern insulin therapy. Mary told me that 'this is not mathematics, it is about humans'. She suggested it could only be a professional decision (whether to get full financial support for analogue insulin), if your own doctor personally decided of you, as he/she knows your full medical history. Mary told that she had been advised not to decrease her HbA1c level drastically as it would hurt blood vessels in the fundi of her eyes - therefore now she has no other choice, but to pay 50% of her treatment. I asked about the government defining the acceptable HbA1c level, and the responses suggested that interviewees were mostly bothered by the incompetence of the state, the presumption that one biological level could apply to everyone ('as if everyone should jump the same height at high jumping') and worries whether HbA1c was a good indicator at all. As we see, affected patients seemed rather annoyed of the new decree. When I inquired about others' opinions they had encountered, I received some surprising answers. Most people do not understand diabetes. Thus, learning about the decree, they could not really make sense of it, a minority even supported it ('at last some regulation against diabetics sitting and gobbling in pastry shops'), though the majority simply showed indifference. Interviewees agreed that after enlightening people about the disease and the consequences of the decree, they were sympathetic and felt sorry for diabetics. 'Acquaintances could easily situate it into the present Hungarian conditions.'

Most interviewees were hurt by diabetologists, who had supported the decree claiming that the recommended HbA1c level is under 7%, because they considered only the theoretical side, leaving out the practical one. On the website of the Journal of the

Association for Diabetics in Hungary, some prominent diabetologists published an article about the "hysteria" surrounding the new decree and its positive medical effects by regulating the 'not sufficiently cooperating' patients. Furthermore a daily newspaper close to the current government, Magyar Nemzet, published an article in defence of the decree. They claimed that, according to the State Health Secretariat, diabetics are practically helped to prevent complications, and 'only secondly', but this measure is also a saving for the state.

On the other hand the Ombudsman and the press closer to the political opposition broadly attacked the decision-makers. The former one submitted a proposition to the Constitutional Court in order to abolish the decree, because he found it discriminative and contradictory to the Constitution (Index). A prominent newspaper, Népszabadság, wrote about the decree as a regulation of patients who are inapt to 'control themselves'. It also included a picture of an insulin pump and the hand of an elderly woman with a sad caption: 'One gets punished for a bad result'. Moreover the International Diabetes Federation also sent Hungary a letter about its concerns. They wrote that 'diabetes is a multifactorial disease (...) It is not only linked to diet and lifestyle, but also to heredity, genes, stress or even poor access to healthy food'. Finally they added that on the long-term it would be definitely an unsuccessful economic measure, because worse medical treatment leads to more serious complications and higher medical expenses.

Targets and consequences

Based on the reception of the decree, I should have suspected it, but I was astonished by the pronouncedly different views concerning the purpose of the introduction and future consequences of the regulation. This was the moment, when I started to feel the genuine contrast between the argumentation of the supporting side and the opponents, my interviewees, whose lives are all affected by the decree to a smaller or greater extent. All my informants agreed that the objective of the decree is to save money in the short run. Some of them even specifically highlighted that the communication of the government was false. A young intellectual woman, Karen, expanded on the 'absurdity' that the decree on itself could help diabetics to regulate their lives. She told me that it was impossible 'without communicating it way in advance and without providing any real help from the state'. The government worded that the decree would be against diabetics who do not have proper self-control (as Karen told me: 'primitive communication works -it is easier to make the decree accepted by imagining diabetics in pastry shops') and that it would result in a healthier society. However interviewees did not seem to agree with this justification. My youngest informant, Zack, pointed out 'noone would have better medical results'; on the other hand he believed that people generally would start to have more and more complications which would prove to be significantly more expensive.

There were also consequences of the decree which were communicated less directly. Most of my informants have insulin pumps, for which they have to pay a considerable amount every year (approximately 100,000 Ft ~ 300 pounds), even with financial support from the state. Some were worried about the future, whether the government would be capable of taking this support and also there was a general disillusionment of politics in the air ('I have no faith in parties'). My informants believed that analogue insulin treatment allowed them to 'live a "normal" life'. Hence they saw the possible change back to human insulin therapy as if 'closing back a bird into a cage'. Zack added that he would move abroad, in case he could not use modern treatment in Hungary. They felt themselves exposed to politicians, who may arbitrarily decide to lower the level of acceptable HbA1c to 7%. I was reminded that the claim of the government, that people who really want to, are able to achieve lower than 8% HbA1c levels appeared to be unbelievable according to statistics. Index published an article in which they claimed that the National Health Treasury do not support the modern treatment for about 20% of insulin users. Fear of what future could bring, both politically and economically, seemed to be an everyday concern, as diabetic treatment is intensive and they perceive unfavourable changes fast.

Special treatment

Discrimination was among the first and most prominent responses I received when discussing the new decree. When I directly asked whether interviewees felt discrimination, all but one people answered with a confident yes. The exception, Zack, told me he did not find this decree exceptionally discriminative, in the sense that diabetics faced everyday discrimination. Although, he added that fortunately his condition was not visible, so he could keep it secret. Others found it very discriminative, because for them diabetes was incomparable to, for example, addictions, where a change in lifestyle could easily lower the need for a certain treatment. 'Insulin, or, for me, analogue insulin, is a life-saving medicine, not a choice of convenience. They shouldn't take my freedom.' Another painful aspect for them was that they felt that the state abandoned them, rendered their lives as secondary or less valuable, because they are provided with worse life conditions. Erica, who does not pay for her analogue insulin therapy now, said she would be ashamed of 'the glance of the pharmacist, when he is looking at the 50% support written on the prescription' - she would hate the compulsion to explain her situation, both to the pharmacist and herself. My informants have Type 1 diabetes, therefore they thought the decree was even more discriminative for them, since it was not their fault that the illness had developed.

Paul Farmer extensively explored structural violence in the poorest regions of Haiti mostly through HIV. Using Galtung's definition he identified structural violence to describe all kinds of social structures that do not allow individuals or groups to achieve their full potential. Moreover it is the 'avoidable impairment of fundamental human needs' (Galtung in Farmer, Nizeye, Stulac and Keshavjee 2006:1686). Farmer was shocked by the visible results of AIDS, which were enabled by the invisible web of structural violence. He wrote: 'structural violence has a profound influence on effective diagnosis, staging, and treatment of the disease' (ibid.). He found out that structural violence, although present everywhere, was a rarely recognized contributor to the desperate situation. In another article Farmer states that possible outcomes of structural violence are 'death, injury, illness, subjugation, stigmatization, and even psychological terror' (2004:308). As he claimed, in his Haitian practice, this meant that structural violence played itself out in the everyday lives and deaths of that certain social group he was researching, the poorest. In conclusion he found that this special power relation 'determines which resources - food, medicine, even affection- are allocated and experienced' (Farmer 2004: 315). Bourgois and Scheper-Hughes commented that 'most violent acts are deviant. They are defined as moral in the service of conventional norms and material interests' (Farmer 2004:318). Another interesting aspect of Farmer's structural violence is that 'the suffering of those who are distanced, whether by geography, gender, "race", or culture is sometimes less affecting' (1996:272) which could account for the invisible nature of the concept. Finally he concluded that 'any distinguishing characteristic, whether social or biological, can serve as pretext for discrimination, and thus as a cause of suffering' (1996:278). Applying Farmer's ideas to diabetes and the new decree, we can spot striking resemblance. Structural violence, in this case, is exerted by the state to diabetics who can be distinguished by a, theoretically, tangible value. Old-fashioned or modern treatment or, in other words, worse or better quality of life is provided for them, by a questionably useful biological definition, which allows their stigmatization to be non-cooperative. This is discrimination in action, which can be carried out, as only a thin layer of society sees through the implications of the decree. Using the comment of Bourgios and Scheper-Hughes, we can add that it is especially violent - it is working on the criminalization of diabetics by communicating this decree to be both a "motivation" and a "saving". If we think further, we can find Jo's concept that 'structural violence becomes a violation of human rights' (2007:5). Jo continues and states that 'human rights' violations (...) manifest themselves as social and economic inequalities'. Therefore if we can identify the new decree as structural violence, which was rendered visible just now, and take into consideration the experiences of my informants we get to see how discriminative and practically unconstitutional the new decree is.

Implications of the decree on character formation

Another focus point of my interviews was to investigate the extent the new decree influenced the social characteristics of my informants. There was a perceivable consensus in the responses of the interviewees. When I straightforwardly asked whether they felt that their HbA1c level determined their image as a member of society, they disagreed. (The only exception was Zoe, who thought that politicians may have had an altered image of diabetics.) My informants refused the idea, because they felt that as people do not understand, or at least do not fully understand, the decree, they tended to stigmatize those less, who are affected. However, Karen told me, she had become less naive and she became interested in the idea of living abroad. Mary expressed her concern that in the last few years she started to survive 'situations of diabetic life' more difficultly. Although specifically the decree seems not to characterize diabetics in a particular way, 'diabetes is still a major reason to render someone as different, which makes any kind of integration harder', Zoe said.

Foucault introduced (2004 {1997}) the concept of biopolitics and biopower in 1976. He described biopolitics to control people on a structural level. His examples of biopolitics included defining acceptable body parameters or, less visibly, interfering with social processes by giving or withholding medicine, insurance, etc from certain social groups. This way performing bodies became fields of power relations. This politicization leads to labelling people like "crazy" or, in this case, "non-cooperating". When biopolitics starts working, it has its apparent consequences. Greenhalgh conducted a research among young, overweight people in California. She identified the label of her informants to be 'weighty subjects' (2012:471) and the biopolitics of the U.S. as 'war on fat' (ibid.). In her article Greenhalgh suggests that 'body is a central measure of human value and core currency of social success' (2012:472). She writes about politics interfering with people's lives, because the governance works on optimizing the optimal levels of body characteristics. This, at the same time, discriminates those, who do not fit the given level; they are looked at as "abnormal" and "irresponsible" "fat subjects" whom it {*the campaign*} seeks to transform into thin, fit, responsible persons' (Greenhalgh 2012:473). Later she adds that 'BMI discourse is thus both normalizing, specifying an ideal or norm and urging people to normalize their status, and subjectifying (...) weight based subject positions' (ibid.). Greenhalgh adds that "failing the BMI test" results in socioemotional suffering; one of her informants worded it 'as if you have failed your body and yourself (...) a number is not supposed to define who we are' (2012:480). Greenhalgh's article shows strong resemblance to actual phrases of my informants. It seems that biopolitics work similarly with overweight and diabetes, because those, who are considered to be "fat" or "non-cooperative" tend to experience similar emotional hardships. Diabetes could be, however, hidden in most cases, therefore they are probably less exposed to subjectification and altered character formation based on looks in their everyday lives.

Conclusion

After finishing the project I re-evaluated several of my initial ideas. I stopped mourning over my epilepsy, which is relatively well manageable, and I realized how lucky I am, since it is really hard to spot that I am "different from normal". Moreover I felt a bit ashamed to not have paid more attention to people who live around me, and are being discriminated despite my attempts to engage with world-changing anthropological ideas. A striking experience of the project was to always look behind the scenes - disbelieving what the politicians say and speaking directly to those whose lives are affected. The new decree of analogue insulin therapy is discriminative, according to my informants, but until now it did not change their characters profoundly. To conclude, I would like to share one of Zoe's quotes, with which I fully agree: 'one cannot do more in a situation like this than to 'have his/her voice heard'.

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