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Mechanisms of power, victimization and autonomy in the health care system

ERZSÉBET TAKÁCS

ELTE Társadalomtudományi Kar Szociológia Intézet, Elmélettörténet Tanszék

ABSTRACT

The aim of this paper is to describe power relations, doctor-patient relationships among the many ongoing changes in health care from sociological point of view. This paper is based on interviews with 17 people who work in various fields of health care. To conduct the interviews as well as to write the paper, a number of concepts and theoretical approaches were resorted to: Dominique Memmi's 'delegated biopower', Eve Bureau and Judith Hermann-Mesfen's notion of 'contemporary patient', François Dubet's concept of institutional programme as well as results of Hungarian health sociology. The main focuses of interest of the paper are role models in health care, the characteristics and consequences of new doctor-patient relations, their manifestations in Hungary as well as potentials of defencelessness and autonomy in Hungarian health care.

KEYWORDS: power, autonomy, patients' role, healthcare

Introduction

This paper is based on interviews with 17 people who work in various fields of health care[1]. The focus of the research wasthe old and new power mechanisms that are interwoven into health care institutions, doctor-patient relationships, victimization and autonomy.[2] The most important theoretical background is Dominique Memmi's research on delegated biopolitics (Memmi 2003, 2010, 2011, 2012a, 2012b) and

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[1] The interviews were done within the research project „The political and sociological use of narratives of victimhood in Europe and Hungary" led by László Balogh. The research and the paper were supported by the University of Debrecen. In terms of the interviews, it has to be noted that they were conducted by students of sociology in their third year, so their depth is limited to some extent. I would like to thank them for their help in the research.

I thank Balázs Krémer for his critical comments of high value.

[2] The interviews attempted at examining the identity and problem of work conditions of health care workers, which are not discussed here. The interview subjects are male and female nurses, GP assistants, district nurses, a paramedic officer, paediatricians, GPs, profession and health care officers who work in Debrecen and Hajdú-Bihar County.

François Dubet's notion of institutional programme (Dubet 2002; Takács 2012). I intend to tackle the current context of health care along the lines of the literature on 'contemporary patient' (*patients contemporains*) (Bureau – Hermann - Mesfen 2014; Pierron 2007; Ménoret 2015) and in terms of Hungarian literature, Éva Orosz's, Zsuzsanna Szántó's, Éva Susánszky's works (Orosz 2000, 2009; Szántó – Susánszky 2003, 2006) as well as TÁRKI and KSH surveys are my primary resources (p. ex. Janky 2010; KSH 2010).

Roles in healthcare

Q: What do you consider the biggest result?

A: (reacting immediately, interrupting the question) That the patient does what we tell them. Diet, for instance, exercises, indeed, they can do the most for themselves. (Nurse)

The expectation of the patients' role in this extract of an interview demonstrates well the current relationship between doctor and patient. The two expectations, often seen as oppositions, are in fact, the result of two medical models.

To this day, the perception of the patient is greatly influenced by the medical model of the 19th century. The objectification of the patient, diagnosing the illness, the ill body with no respect to the individual as a human being is still a characteristic of medical practice (Pierron 2007). English and French literature links the spread of the word 'patient' to a characteristic phenomenon of health care: the patient is a subject that undergoes medical treatments[3], specifically dependent on biomedical institutions and doctors (Pierron 2007).[4] The medical skills to cure alone and authority are acknowledged by society by the 20th century, and this process was accelerated after WWII with the spreading of antibiotics and the development of pharmaceuticals. Medicalisation along with technicization of medicine further

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[3] In the 20th century in the English language *patient* comes from the Latin words *patiens* (endure of something, sufferer) and *patior* (allow, acquiesce, suffer)

[4] The biomedical model traces illnesses back to physiological disorders, measurable biological variables with certain agents - germs, viruses and parasites or cellular, molecular disorders in the background. The biomedical model treats illnesses not ill people as it looks at reality from a scientific perspective: what is not somatic or cannot be reduced to the level of somatic processes, cannot be explained and therefore, it is not realistic. Conditions with severe subjective symptoms that have no tangible biological (physiochemical) reason are not considered to be illnesses. The patient is a passive endurer of medical procedures; as the body is a machine, it needs repairing. The more advanced technologies and scientific procedures are, the better chances restoring health has, and that can only be achieved by procedures.

increased doctors' responsibility in healthcare,[5] while patients were assigned the role of being accepting, cooperating and subordinate. This is fundamentally the ideal doctor-patient relationship that was first modelled by Talcott Parsons (Parsons 1951: 436–437).

Parsons analysed the relationship of doctors and patients, separating their rights and duties, clearly from a doctor's perspective. As being a doctor is a profession, „the doctor is to place »the patient's well-being« above his individual interests; he strongly opposes »commercialism« which is the greatest and most insidious of evils. The medical profession is to distance itself from »business«" (Parsons 1951). One of a doctor's duties is to be specifically skilled in terms of technology, which means they are to practise their profession and attend their patients with outstanding knowledge and professional know-how. As professional knowledge provides doctors with a privileged status in society, this power – as well as relations in the feudal medical community – influences doctor-patient relationships. It is also the doctor's duty to do their job objectively, without emotions. They may feel sympathy but not empathy towards the patients. Another obligation is not to be selective in terms of their patients according to the principal of universalism: a doctor is to attend each and every patient in a similar fashion, to the best of their knowledge. According to the requisite for functional specificity, the doctor is not to be concerned with the patient's private life and therefore, consider any of its aspects.

In the perfect realization of the functionalist approach the obligations of a patient are complementary of this: the patient is to wish to be cured, they are to turn to the doctor and cooperate with them. In Parson's view the doctor-patient relationship is fundamentally hierarchical, as doctors are in possession of specific and thorough knowledge which is a guarantee of healing, and the incompetent patient is to follow the doctor's instructions. Thus the doctor's rights extend to the examination of the patient's entire body. This along with the fact that doctors can perform otherwise unusual procedures leads to a feeling of defencelessness on behalf of the patient. Another right of the doctor is autonomy, as that is the only way to treat the patient appropriately, as well as authority, as the patient hands over the control over his own body to the doctor to a certain extent. However, the multiple manifestation of defencelessness does not mean that the patient is deprived of all rights: they are not responsible for their illness, and they are relieved from performing their social roles (as long as the doctor legitimizes the absolution).

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[5] The medicalization was enhanced by the spreading of chronic diseases. The best example for that is depression that is widespread in society and its mental pathology is accepted as a chronic disease, and its cure can primarily be achieved with psychotropic means. See: Ehrenberg 1998.

I feel absolutely equal with my patients. Well, our relationship is that of equals, er, maybe it was stupid of me to say it like that. There is that carer-caree relationship, so I'm a bit above them (laughs). So not quite equal, but still equal. (District nurse)

Parson's model - which assumes the patient's unconditional trust towards the doctor as well as the doctor's absolute power and describes interaction as paternal - is questioned more and more today.

New notions of patient as a client are introduced here based on a paper by Eve Bureau and Judith Hermann-Mesfen, who compiled two special issues for *Anthropologie & Santé* to elaborate on the subject.

The authors describe patient-doctor relationship as a result of four important changes. Firstly, the extension of the idea of illness and opening medical science which was closed off for a long time brought along treating the patient as a person with all the implications of that. As opposed to the approach of objectifying the patient, today subjective experiences of an ill individual (can) contribute to the clinical process. The concept of health is not defined by medical thinking that focuses on a specific illness, but is looked at in terms of the full physical, mental and social well-being of the individual. At the same time, health and staying healthy is the individual's responsibility; the individual is the one to ensure their physical and mental health by acquiring the „right" behaviour. This is parallel to the opening of medical science which is on the one hand a result of politics entering medicine, and the democratisation of medical information on the other (due to the internet). Thirdly, it is also due to the appearance of new participants individuals get in contact with in order to stay healthy. This partly entails the enhancement of a parallel, „non-conventional" medicine that started to develop in Europe in the 1970s, 1980s. Medical and therapeutical pluralism distributes a number of medical tasks among the professional and laymen representatives of medicine (Cohen – Rossi 2011).

The second change is questioning the efficiency and role of biomedicine. In the beginning of the 20th century self-help groups in America were born out of the criticism of biomedicine. The scandals in the 90s (infected blood, growth hormones and dioxin poisonings) caused a crisis of confidence in biomedicine: due to professional errors, a lot of patients lost trust in the vocation. In addition, but also independently of all that doctors have sensed a loss of trust and status, especially since the 2000s. As a result of shaken legitimacy, doctors could not afford any more to decide themselves what is good for the patient, they had to convince them about it (Béraud 2002).

Many theories examine the shaken trust in institutions and experts in late modernity. Anthony Giddens thinks the belief and trust in expertise which used to be the organising principle of social hierarchies was compromised in late modernity.

This loss of trust transformed institutions that are built on expertise.[6] As expertise did not need justification earlier, today it has to be made available for laymen, in a way that institutions become ones that are in constant interaction with individuals, are reflective and flexible. Institution that are reflective, i.e. use knowledge about social context, provide customized, flexible solutions instead of general (and therefore) rigid ones (Rényi – Sik – Takács 2014). Only such reflective institutions are able to handle the loss of trust in expertise (Giddens1990; Sik 2013). Compromised trust in doctors' authority is also sensed by medical workers who were interviewed:

Now I am not sure how to put it, that doctors are considered a more prestigious part of society, but I think what used to be decreased by now, sometimes people even freeze down if they know what my job is... Because, what does one hear on the news - always bad things (GP)

I work at a paediatric department... parents, who often do not appreciate, but it is part of it, we must accept... they often speak to us with a rude tone. (Paediatrics, nurse)

There is also an example of blaming the loss of trust on the impersonal nature of the system, but not on the ones who practise the profession: „It happens that they are mistrustful, but not towards us, more towards health care." (medical assistant, hospital nurse). It is detectable that with the desacralization of the medical profession, the special status of the medical community is also damaged, as its exclusive position, its distance from the laymen decreases, and its immunity from laymen's control is also questioned.[7]

The third change is the democratization process of health care, health care institutions becoming individual-centred or its singularization from a different approach. This can be detected in the transformation of medical practice, especially in initiations of self-management of patients with chronic illnesses. In the 1980s more and more doctors thought that individuals are potential enhancers of their own healing, so they shared their knowledge to a greater extent, so that they could look after themselves more (most often in case of diabetics and kidney deficiency). These „self-medicating" patients „often acquired the most sophisticated technical skills in order to be least dependent on biomedical institutions and to preserve their personal autonomy" (Bureau – Hermann-Mesfen 2014).[8]

At the end of the 1990s in America „responsible" „illness management" programmes appeared, and they were meant to provide patient with as much

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[6] For more information, see Giddens1990; Sik 2013; Rényi – Sik – Takács 2014.

[7] In Éva Susánszky and Zsuzsanna Szántó's view the medical community will stabilize in the future with the decrease of fights between interest groups and the strengthening of team spirit, which might lead to lessening control by laymen. See Szántó – Susánszky 2006.

[8] Therefore, expertise became laymen's expertise, and this process also took place the other way round due to the pressure from organisations of HIV and AIDS patients. Firstly, laymen's knowledge became a type of expertise due to movements organised around these diseases (and patients), but today there is laymen's knowledge in connection with a number of pathologies and diagnoses (e.g. autism).

information as possible for the sake of efficient cure in case of illnesses such as asthma, diabetes, hematologic and cardiovascular diseases. That initiated „expert patient" programmes.[9] The idea of an expert as such was placed out of professional contexts, for which the best example is the emergence of „layman expert". Typically, the notion of 'users' is also more and more common in health care.

The fourth change is the advancement of individualism in health care, which was touched upon in the proceedings. Autonomy and to right for self-determination, the responsibility of the individual, sharing power and knowledge, equality, respect and acceptance all assign a greater importance to the individual. The social development in the second half of the 20th century described by Alain Ehrenberg, in which autonomy becomes a general norm that is present in all areas of society, and whose buzzwords are individual initiative and freedom of choice, does not leave health care intact (see Ehrenberg 2010).

Defenceless and Control, Power and Autonomy

The theories above provide explanation for many aspects of social changes. However much the patient is placed in the centre of curing, they are not the ones in the centre (Bureau – Hermann-Mesfen 2014). While there have been many initiatives for a more equal doctor-patient relationship, it is rather unequal to this day. In many cases the patient is just not considered as a factor – they are not asked, for instance – and are not considered as a person. The doctor's exclusive authority has not ceased to exist, either (Jaunait 2007; Bureau – Hermann-Mesfen 2014).

The doctor's role is specific, as healing i.e. life itself is in the doctor's hands. That has a direct influence on the roles of a doctors, the closed off nature of the medical community and the wide social gap between the medical community and majority society. All that considered, models of doctor-patient relationship models are based on communication, sharing competences, and trust and power relations. The most typical one is the traditional-paternal model, which is an asymmetric relationship based on the biomedical approach, in which the patient fully acknowledges the doctor's competence and dominance. The conflict model of the doctor-patient relationship is based on the notion that the participants are competing and have opposite ways of thinking. One of the reasons lies in the different interests of the two parties, for example in case of an illness career when the patient wants to be/stay ill, or vice versa, when the primary aim of the patient is to recover, but they feel that the doctor does not do everything to achieve that (which can be derived back

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[9] In England, for example: http://www.nhs.uk/NHSEngland/AboutNHSservices/doctors/Pages/expert-patients-programme.aspx (in: Bureau – Hermann-Mesfen 2014: footnote 7).

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not only to a lack of means or overburdened doctors, but to misleading interactions or misunderstandable information). The main argument for the conflict model is the traditional, feudal relationship between doctor and patient, in which tension and conflicts are inherently present. The third model is the so-called consensus or bargaining model, in which the doctor gives up a part of his autonomy or authority and makes his professional work controllable (see Szántó–Susánszky 2006: 125–127). In practice doctor and patient seek a consensual solution together after the doctor's explanation.

There must be a certain extent of subordination between patient and doctor, how shall I put it, this is not the right word, but I should dictate, he should complain, that's his role, and then I say what I think. I often tell them to share how they see it, sometimes very clearly, so when we are thinking together, I treat them as equals, but I'm sure there are situations, when there is a feeling of defencelessness, but it depends on the situation. (GP)

The question is what making a decision (together) really means in practice. What do doctors, nurses mean by the patient's autonomy or participation? Sharing information or the responsibility of decision-making can vary: e.g. manipulated (when the patient is not really a participant),[10] it can be characterized by various forms of symbolic cooperation (tokenism) or the control of the patient (actual participation). In case of tokenism, the patient is well informed, and therefore they can understand the nature of their illness, procedures, but they cannot make a decision. In fact the only control of the patient manifests when it comes to sharing power and the actual influence of the patient (Bureau – Hermann-Mesfen 2014).

Sylvie Fainzang wrote a book about the way of information use in terms of the doctor-patient relationship. The author paid special attention to lies and withholding information when analysing the problem of the patient is informed (Fainzang 2006).[11] Fainzang's work is especially interesting, because in spite of the research conducted on patient-doctor communication (as well as withholding information and lies)[12] since the 1960s it was examined from a psychological point of view. Fainzang deprived the issue of psychology and focused on social mechanisms. She found that doctors uniformly share the same principle i.e. „actually true information

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[10] One example taken from the interviews: *"There are some who think they make the decision independently, but what you need more, the doctor needs to make it look like that the patient makes a decision independently. That is why we need to tell them all the pitfalls, in order to lead them to their decision, the right decision."* (Occupational health-care professional).

[11] The moral dilemma of (white) lies and keeping quiet came up in more interviews. *"If it turns out to be a tumour, that is quiet a dilemma, whether to tell the patient or not. Usually the family is consulted in cases like that. Not all patients can accept that, and that is quiet a big dilemma, whether to tell the truth or lie to them."* (Assistant, hospital nurse)

[12] A typical example of lies is the doctor's announcing „we take a break in therapy", which is in fact the failure of the treatment.

is given at the patient's request" (Fainzang 2006). Doctors think they can handle the patient's need for being informed without problems by means of various signs e.g. with metacommunication.[13]

It turned out that doctors give more detailed information - for example about the risks of certain treatments - to patients with socioculturally high status, even if they do not ask anything. On the other hand, patients with low status are thought to be ignorant, because they do not ask the „right" questions, or they are afraid to ask questions in hospital environment. (And doctors think, if they do not ask, they do not want to know.) More educated patients are better at acquiring information - for example, they ask the same thing more times in different forms - and they also try to read metacommunicative gestures.[14] Lies have their own consequences: patients lose trust in the doctor, which leads to „medical nomadism".

At the same time patients themselves lie, often by keeping quiet about symptoms or making them sound insignificant in order to avoid examinations or having to face the severity of their condition.[15] The interviews reveal that patients' lies are especially frustrating for doctors: *„If I encounter a lack of trust, that's the worst... if they lie, that kills me. Is someone is being dishonest to me." (GP)* However, majority of the lies is in fact misunderstanding.[16] In doctor-patient communication sharing information is often accompanied by misunderstandings, which can be traced back to ambiguity of terms. For instance, there can be a diagnosis that causes the greatest despair for one patient and unjustifiable joy to the other. There can be misunderstandings due to over-interpreting a conversation, but beside linguistic incomprehension, a

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[13] The importance of metacommunication and its perception as a special, (also) medical skill came up in the interviews as well. *"GPs have a sort of sixth sense which cannot be defined, but it is innate, just like body language, so one needs to have an insight into the human character, which is characteristic of this profession, and especially the profession of a GP." (GP)*

[14] Placing a hand on the patient's shoulder for example indicates the severity of the condition according to some patients.

[15] According to the French author, all that is more characteristic of lower social classes. Even so, I do not believe that anything similar could be argued in terms of Hungary, given the lack of researches. Keeping quiet about certain symptoms, manipulating the diet prescribed, varying the medicine, withholding test results or insincerity with the doctor cannot be assigned to one specific social class, in my opinion. However, similarly to the attitude of trust/mistrust, there can be variations according to different sociocultural backgrounds.

[16] It came up in the interviews many times, that some subjects had issues with especially Roma (minority") parents, who *"did not cooperate"*, *"rant about everything"*, *"are offensive"*, *"don't give medicine to their children"* (Nurse, Assistant, Paediatrician). One doctor recognised that it derives back not to habits or cultural reasons, but social ones originating from disadvantaged position and poverty. "There are difficulties and I mean (thinks) mostly Roma parents. They are not really cooperative, do not take the advice we try to help them with... minority parents who don't really take advice, don't give children the necessary medication. And it is not only up to them (eer...), the difficulty is not that they are not cooperative, but the money is little. There are no financial resources to buy the things, medicine children need. The other thing is, they only bring the child, as a final resort to the doctor, when the problem is big. Unfortunately, there are more and more." (Paediatrician)

difference of perspectives can also cause problems. The following interviewee (a GP) emphasizes the importance of communication:

Here one needs to assess the cognitive abilities, in other words you need to assess how well-informed, forgetful the patient is, so you need to know the patient, what you advise, what words you use, because everybody nods here, I see, I see, then you ask and half of them couldn't repeat it, so that's about it, informing and communication is important. (GP)

Fainzang's research shows that there are people - both doctors and patients - who think being fully informed is preferable in order to face the illness and choose the most suitable therapy. However, there others (doctors and patients) who think important information is only the doctor's concern in order to avoid uncertainty and to keep hope alive (Fainzang 2006). All in all, information and involving outsiders can mean a lot of things; patients' real autonomy can only work by implementing general moral changes (*agency, empowerment,* solidarity) (Bureau – Hermann-Mesfen 2014). Patients are not able to acquire the new role without doctor's real participation and conviction:

This doctor-patient relationship is obviously two-sided and it is mostly the doctor, who can change anything about that. If the doctor does not really care, the patient sees that, if he doesn't care, or not really, not honestly, the patient perceives that. And then that doctor-patient relationship is not good, nor can it expected to be. The patient will not change that, because he is ill, always anxious in the doctor's lounge, and always afraid of something, and I can ease that, the doctor, so I can give him what makes him less anxious and trusts me. (Health protection officer)

Recognising and acknowledging that is especially important, because tendencies can be detected – not only in Hungarian health care[17] – that are opposite to the enhancement of autonomy. Dominique Memmi examined England and France, extending the research to twenty-seven countries and came to the conclusion that a more tyrannical and more conservative treatment is common in health care, which can be tracked in the discourses of preventative campaigns since the 90s (Berlivet 2004; Memmi2011, 2012b). Based on research of a decade, the author thinks that after a period when the individual was given the choices after a conversation with the expert, i.e. trust was placed in them, today we can again observe relatively authoritarian procedures. Certainly this does not mean a regression to the authoritarian forms before the 1960s, but a third way of influencing behaviour can be seen, for example in the form of expert volunteerism.[18] Drawing conclusions from

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[17] See value researches on autonomy and the desire for autonomous action among the Hungarian population: Ságvári 2012; Kapitány – Kapitány 2012; Albert– Dávid 2009; Keller 2013; Tóth 2010. For the extremely depressing researches on the youth, see Magyar Ifjúság 2012; Takács 2014.

[18] Memmi's last book in 2011, as well as her last published research on the ethical problems of abortion (about this, see Weber 2009) was intended to demonstrate this idea. (One of the earlier subtitles

the first two period, today „imperative ways of *legitimate* behaviour in terms of the *right* use of one's body" can be seen, which prescribe or suggest about a specific area, how to face life and death *correctly*, how to proceed *correctly* in the borderland of life and death, i.e. in health care (Memmi 2012b). Memmi thinks expert volunteerism can be so powerful, because the state - in addition, perhaps some societies themselves - hand over decision to doctors (and to a smaller extent to other participants of health care) that cause social uncertainty, anxiety, and determine our health and lives.

Memmi's notion of „delegated biopower" arrives at the (neo-Foucaultian) proposition that today's supervising state hands over supervision to peripheries of public services, representatives of so-called „liberal professions" as a special way of governing (Memmi 2012a: 77). During consultations that are obligatory in case of procedures concerning our bodies and lives, representatives of the medical field provide patients with information, they explain the meaning of medical test results. At the same time they are in charge of controlling the motivation of the decision, which enables the refusal or suspension of the procedure, if it is not relevant (Memmi 2012a: 77). However, Memmi talks about double delegation, as the rational managing of one's body is delegated to the individual by the government. This means that theoretically individuals are able to assess their bodily conditions, their risks and estimate the financial costs of their correction.

The health care system is trying to supervise and control as well as to get rid of certain aspects of responsibility. In addition, the supervising and controlling function of the system is imperfect. One of the reasons is that health care is underfinanced, on the other hand doctors and medical staff as such are overburdened: often they simply do not have enough time for the patients. There are patients who do not want to develop a close(r) relationship, for example to get involved in a consultation (either because they have already made a decision about what they want or because it is too overwhelming emotionally or because, as mentioned earlier, it is challenging in terms of language). Control is a pressure for the doctor as well, and the patient

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was *Professional volunterism serving identities.*) She found that doctors and obstetric workers persuade (sometimes push) certain practices when parents have to deal with the bodies of dead fetuses and infants (to look at their dead babies, children, „just as if they were asleep" or have them taken pictures of - often with a sleeping blanket, or touch them). This is all based on „the idea that mothers need some time with their dead children so that they could process the loss" (Memmi 2011: 98). In her research she found that these practices were not born out of common need or pressure from the grieving family (on the contrary, in spite of that). She thinks in this case „the legitimizing practice proceeds empirical verification", i.e. institutional efforts are made to „legitimize scientifically something that already exists in practice" (Memmi 2011: 73). This is not about a collective social need, but a group of medical workers' (especially obstetricians') systematic advice based on medical literature. In such cases obstetricians, doctors - and not the patients themselves - identify women's pain, culpabilisation, psychological suffering. This is controlling behaviour related to life and death, in which it is a premise that patients cannot do grieving alone, only with help (Memmi 2011: 115–123).

may display a willingness to cooperate and then act differently right after leaving the room (Memmi 2012a: 78, 82, 83).

There are many other authors beside Memmi, who warn that the in health care „responsible" individual attitude, the decision competence imposed on the individual may lead to experts' tasks being delegated to patients in order to ease their workload. Patients' (relative) participation in decision making may even absolve doctors from taking responsibility (Bureau – Hermann-Mesfen 2014). In the meantime health care issues today tend to be more and more separate from the state. Besides, patients' lives are becoming even more complicated. The boom in medical technology and increasing number of experts due to technical specification often ignore each other's ideas, procedures. Patients have to choose from all those, so their task is becoming more and more complicated. Moreover, their administrative tasks increase, and they are divided among various medical centres and institutions.

At the same time, the idea of a responsible patient is not contradictory to biomedical norms: today patients („contemporary patients") are legitimized within the system, if they are competent, rational, concise and not very emotional, i.e. „good patients" according to the professional staff (Wilson – Kendall 2007: 426–438). However, less authoritative means have their weaknesses: one is trusting the self-control of patients. Assuming such an attitude is a central problem of institutions and of the profession, anyway. Memmi arrived at the conclusion in her research that the „controlled habit" that ensures the operation of institutions is in fact a characteristic of a social class: only the middle class adapts rationalised management of body as one's self (Memmi 2012a: 82–83).[19] As the „good patient" behaviour is a characteristic of the middle class,[20] the „contemporary patient" attitude is more and more common among the most educated and informed patients. Patricia Wilson and Sally Kendall emphasize that this phenomenon leads to an increase of inequalities, as those who would really need to leave the role of a defenceless patient are the ones who are unable to do so (Wilson – Kendall 2007).

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[19] The author notes that this system cannot deal with patients like repeated aborters, abortion pill consumers or with those who would not take medication when dying.

[20] This was confirmed by the interviews. The least problematic clients are considered to be educated ones (especially if they are young), although there were some, who had different views. *„It's easier with those who are really ill, they... interestingly not impatient, they thank you and wait for the moment when help arrives and happens, they don't ask unnecessary questions. ...as I mentioned before, the really ill people don't try any tricks to get the examinations over with sooner, or to get into the best institutions possible." (Paramedic)* The „good patient" – according to the interviews as well - is someone who trusts their doctor, does as advised, keeps the instructions and does everything to recover. The „bad patient" is mistrusting or simply lies, does not keep instructions, rants, „knows better", or too well-informed, and is responsible for their own (or their children's) lives due to their way of living. These opinions are not different from those of the French colleagues (see Dubet 2012: 205), the difference is Hungarian patients' impatience, even aggression, as well as the tension resulting from the gratuity system.

The notion of contemporary patient in light of the interviews and domestic conditions

Health care appreciates two different attitudes in today's patients that are completely the opposites of each other. The patient is to display actively responsible behaviour (*empowerment*) for the sake of their health, but they are to stay within the boundaries determined by professionals. Placing the patient outside the medical system even partly is contradictory to the practice of medicine, whilst science and technology have developed to such an extent over the past decades that patients find themselves in particularly a dependent position due to differences in knowledge of doctors and patients.

It is interesting to see that workers of the medical profession hardly reflected upon this aspect of defencelessness. Nurses saw defencelessness primarily as physical in nature, assistants working in various fields interpreted it as a consequence of socioeconomic status (Roma, old people, people living on farms). Getting undressed as a typical example of defencelessness came up in many interviews.[21]

Patients are completely defenceless in health care, because let's just say, one goes to a hospital and he doesn't even know what is done to him, and nobody is saying anything to him. What's more, he has to take his clothes off. (laughs) So I think that is vulnerability.

To a certain extent, some social groups are defenceless, er... (sighs), like old people, maybe minorities, I mean Romas, people with low education, they are surely defenceless to some extent... People in bad financial situation, for themselves, those who are not able to stand up for or fight for themselves. (Dental assistant)

It is just a vulnerable position, one comes here as a patient. For one thing, you are defenceless, you have to get undressed. Then you have to share your problem, your illness, there are people who are anxious about that, think of illness as some kind of sin, I don't know, there are people who don't talk about the illness because it is like as if the asked for it, but they experience it as a sin. (GP)

Defencelessness often causes indecisiveness: „vulnerability might be... the reason that he does not get to, ha can't decide..." (GP assistant about patients from farms). In terms of patients' autonomy of decision-making, interview subjects have very different opinions (which of course might be due to the fact that they work in different areas and do different medical work). A hospital nurse says

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[21] *"If someone goes to a doctor's surgery, it does not matter who they are, first of all, they have to remove their clothes. I could be, I don't know - that the patient is a man and the doctor is a woman and some people are affected by that, but the patient knows they have to get over that... that is a source of stress or distress in the patient. Now obviously, I mustn't laugh at them, if I don't know, something is hanging, or something is like... This is unpleasant, and they can say I'm vulnerable, which is true." (Health protection expert)* See also Sándor 2016.

they usually find it very difficult [to make a decision]. So when it's about something very serious, important, patients tend to panic, then the family or most doctors help... [What influences the decision is] where the family stands, as well as how the information which he is facing is presented. (Assistant, nurse)

A GP on the other hand, says

they make good decisions, my patients - at least those who are well-informed, they like to examine things from different perspectives, ask around, maybe for second or more opinions, sometimes discuss things, or consult more professions, so this is a basic thing people like, one opinion is not an opinion, one line of defence is no defence at all, but I think they make decisions well. (GP)

As we saw earlier, influencing the patient to make the „right" choice for his health is not an ethical problem for some of the doctors:

I think, a completely independent decision cannot be expected or allowed, because them taking the meds or not, certainly there is no-one standing there to put them in their mouth, but you must explain it to them, if they don't take them, I don't know, high blood pressure can lead to the development of complications, a heart attack, a stroke or something, and it will be too late,... obviously the decision is theirs, but I have to deliver it in order that they make the right choice. (Health protection officer)

Clearly, the autonomy of decision-making is questionable in itself. In the interviews autonomy of decision-making often comes up with respect to defencelessness. Marie Ménoret arrived at the same results when analysing English and French literature on autonomy in terms of health care. She says autonomy primarily comes up as an opposition to physical defencelessness of the patient, or in the peculiar context of chronic patients, because developing means and practices that enable patients' self-curing is gaining ground (Ménoret 2015). Ménoret also arrives at the conclusion that real practice oscillates between *empowerment* and control.[22] In Hungary our interviews (not representatively) do not seem to indicate that. It is worth noting that it was only mentioned in one interview in terms of expectation towards patients that „the patient should be able to help themselves and this helps them heal more". (Nurse)

Autonomy is a central problem of both biomedical and contemporary patient models. However, there is much less emphasis on patients' behaviour in the literature on the subject, despite the fact that for some patients, illness is clearly a liberating possibility, an escape route. These people are partly ones who cannot be part of social division of labour due to illness, and after a while they find themselves being socially excluded. They find it easier to justify unemployment with their illness, they identify themselves with this social role as part of the process and they expect the

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[22] For that, see also Bureau – Hermann-Mesfen 2014.

healthy to provide for them. It may be argued that their illness has become their job (Herzlich 1973; Szántó – Susánszky 2006: 77).

From this respect, illness is not simply an illness. It is important what the environment considers an illness, and who is held responsible for the development of the illness. Developing some diseases in certain groups seems natural, so they are not considered illnesses. (For example old people often feel unwell, dizzy, a smoker coughs more, so people do not automatically turn to a doctor). This common people's philosophy of illness is not contradictory to the medical approach, just as the phenomenon that patients are not interested in the physiological background of a disease but in understanding the reasons for the changes in their lives.[23] The biomedical model is not suitable for that; that is why various ways of alternative medicine are popular (Szántó – Susánszky 2006: 77-81).

This paper cannot discuss what motivates patients to cooperate, take on an active or passive role in the curing process.[24] The interviews also reveal that patients in Hungary tend to develop a consumer attitude, mistrust towards the system as well as acquiring information about alternative options.

People nowadays are „better" at health issues just as at everything else. Almost everything is available on the internet, and that goes for medicine as well. Of course there are good things to this, but we often see cases when the patients have already diagnosed themselves and come in more scared, which fortunately, is usually wrong. Many „cures" are available, most of which is futile, but patients don't know that. (Nurse)

Of course, a lot of them say that they read this and that on internet forums, ... how to treat it. There are doctors who fly into a rage when they hear 'internet' and what has he read again. This shouldn't be looked at like that, because if I were ill, I would read, I would try to find information, obviously people used to look it up in pocket cyclopaedias. They often come up with good things, but often the profession has such a wide scope that they read everything about the disease, and I would be lying to say that I can be up-to-date in all areas. The bigger problem is that I often say frankly that I don't know something. Or they can come back in a week, I'll look into it and will know more. (GP)

Another two explanations in the literature on changing doctor-patient relations is the laymen's assertiveness due to individualization, the importance of subjective experiences because of common chronic diseases,[25] as well as alternative solutions

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[23] Éva Susánszky and Zsuzsa Szántó think the difference between scientific and laymen's thinking is not professionalism, but aims, see Szántó – Susánszky 2006: 76–77.

[24] For more on *not* turning to doctors, see Éva Susánszky and Zsuzsa Szántó's summary on earlier research: Szántó – Susánszky 2006: 81–82. The main reasons are the costs of travel and waiting, then mistrust towards the doctor and finally, avoiding facing the illness.

[25] Although a GP Assistant's remark might be a reference: *"patients are more enlightened about their own illnesses, than the nurse. They can say things, and you just stand there with your jaw dropped."* (GP Assistant)

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resulting from the acceptance of the impossibility of full recovery do not come up in the interviews spontaneously.

Problems of (sense of) mission in contemporary health care

„At an outpatient clinic on is attended, examinations are made, but they do not say anything. Many times mothers bring the test results here, because the doctor did not say anything." (District nurse) The third group of participants in doctor-patient relations is the nurses, assistants as well as district nurses from many respects. Nurses are transmitters between patient and doctor; they have to take on the roles of a subordinate and of power position at the same time.

You are often expected to know everything like a doctor, they don't see it is not my competence and I can't give them medicine, and they don't understand why. And you say you mustn't do that because I'm not a doctor and then, of course you can, you know better, and it is problematic, because there will be a conflict between you and the doctor. And then I try to tone it down, that they shouldn't say that, because it is not true. So people... you know, this is the patient-nurse-doctor conflict. Sometimes the nurse is appreciated more than the doctor of the district. It also depends on the doctor. In many cases they trust you more than the doctor. I don't mean in terms of medical things, but they tell me more... Curing, medical treatment and caring cannot be separated. (GP Assistant)

It is the nurses' and assistants' task to create an atmosphere of intimacy with trust, in which patients can open up. Dubet explains it with the dual heritage of institutions (religious-charity as well as academic), i.e. nurses have to meet the „male-like" requirements of the scientific and technical medium as well as have the „typically female" characteristics of being understanding and compassionate that is needed in helping professions.[26] At the same time they are in possession of information that gives them power over the patients. However, they often describe their professional duties by being subordinate and obedient to the doctor.[27] Nursing is seen as one of the most exploited professions because of constraints and necessities due to work conditions and organisational structures, social inequality and low

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[26] Dubet 2002: 195, 204. According to the author that is what makes it especially difficult to have the qualities of nurses acknowledged.

[27] Dubet's research shows that nurses often criticised doctors from this respect: doctors are too impersonal, too indifferent to patients, too cold and condescending to nurses and they think "they can do anything". At the same time in the literature nurses have some kind of nostalgia for a good boss, who is competent and humane at the same time, for whom their team would do anything. In Dubet's focus groups there was no such sentiment, his interview subjects found this picture grotesque. In our interviews hospital workers and the paramedic emphasized the importance of the team working together and the trust placed in colleagues.

salary,[28] underfinanced health care, lack of (efficient) self-representation, ethical dilemmas, obligatory overtime, institutional abuse (either on behalf of patients or due to vulnerability to institution hierarchy).[29] The most important task of nurses is to take care of the well-being of patients, even at the cost of their own (Martin – Alderson 2013):[30] *„I always try to aim at 100%, the maximum, sometimes I don't succeed, but usually I do." (Assistant, hospital nurse)*

In our interviews we tried to assess the extent to which a sense of mission is present among health care workers.[31] In Dubet's notion of „institutional programme" dedication and self-sacrifice on behalf of people with socializing professions is essential.[32] Institutional programme is in fact a certain type of socialization, a socialization principle that lies on three pillars: a mediator between universal values and individual characteristics, socialization aims at imprinting norms whilst enables the individual to be free. The scheme of the programme is simple: in the beginning, values perceived as universal shape the individual and individuals operate institutions by integrating these values. The individual becomes a subject, conformed and able to criticise and the same time. This programme ensures and implies social coherence. Dubet goes into detail what holds (used to hold) the institutional programme together and describes its ideal operation. The institutional programme is disintegrating; its „charm" to conceal the contradictions of basic value does not work any more.

Social work on others becomes problematic from many respects for Dubet. On the one hand, there are questions around the definition of public good: as there are increasing contradictions among traditional operational principles of institutions. On the other hand, the bureaucratic model losing ground on organisational level

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[28] At the same time a shortage and insufficiency of human resources is a (global) crisis phenomenon in healthcare.

[29] An example from the interviews for frustration: *"But eeer... the problem with Hungarians is that they worship the doctor. Because in abroad, eer, the nurse is more appreciated than the doctors, because the doctor just gives a diagnosis, says what to do and how to do it, what to give, how to give, what medication etc. And the nurses do that. It is not the doctors who take care of them, but nurses. Doctors are only there in emergency. At life threatening situations, operations etc." (Nurse)*

[30] Assistants are in a special situation as they often have to take on the role of a lightning rod: the tension between doctors and patients often boils down on them, whilst "this profession is rather a dead end". (Female dental assistant) The occupational health-care professional who deals with health protection and prevention complained about a lack of prestige, appreciation amongst structural disfunctions.

[31] I can be said that for most our interview subjects say the motivation still comes from this, even GPs feel the same way.

[32] Tackling the problem is not without history in Dubet's sociology (For this, see: Dubet 2005; Takács 2012). The concept of (decline of) institutional programme is a result of a comprehensive research: three-hour-long conversations with nurses, social workers, teachers of various levels and mediators as well as with focus groups, repeated 6-10 times in Bordeaux, Paris and Pau and recorded material from a number of interviews made it possible to draw the above conclusions.

and the modernization of public services, which is accompanied by new demands in terms of professionalization, development and acknowledgement of partnerships all destabilize institutional implementation processes. Thirdly, on a social level the pluralization of individual identities confronts institutions with new categories of the population - „persons" and „clients", to which they have to adapt to: they have to respect the first one and meet the demands of other (Laforgue 2009). Besides, the real problem is that the „institutional programme" requires discipline, devotion and transparency from those who wish to join, as socialization work is a mission as well. These socialization professions are shaken to their core as their representatives face changed conditions and transform themselves. The idea of devotion and self-sacrifice clashes with the authenticity principle of the individual; questioning authoritarianism and authority compels the individual doing socialization work to do „constant justification work", being left to rely on their own charisma or charm instead of authority, which is not necessarily available to them. It could be argued that they are in a state of constant confusion of roles, but the roles themselves are not defined, so they have to adapt all the time. Actors of institutions often do not base „work on others" on the criteria of efficiency, fairness or authenticity, which might cause a moral dilemma, on the other hand it can trigger different ways of intervening or seeking for help.[33]

Doctors and workers of health care do change themselves (or are compelled to change) along with the changes described above. It came up with interviews with nurses that doctors establish a relationship with patients to a lesser extent,[34] and due to more technical procedures, less clinical patient-oriented clinical research is done in diagnostics or therapy. Doctors' attitude is probably greatly influenced by the fact that they have to deal with more old age or incurable diseases due to the phenomenon of an ageing society. The final conclusion of our interviews (which were originally recorded to gather information) is that global changes have a greater influence on the power relations of doctors and patients than domestic conditions such as burnout - which can also interpreted as a sign of crisis, increasing hopelessness among health care workers, lack of trust toward everyone involved in the system, lack of reliable, realistic vision of one's future, emigration, hospitals in debt,[35] learned powerlessness, and total vulnerability of certain social classes. Exploring all those could be the aim of a future research.

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[33] The question Dubet's interested in is what follows after the disintegration of institutional programme? What acting abilities and identities remain? Can we base social relations exclusively on individuals and on those contracts that are made willingly?

[34] One of the (many) reasons is the reduction of the time of hospital care.

[35] One of the moral dilemmas that arises when practising the profession is a comment on the insufficiency and limits of resources: *„When I started my practical training I was surprised to see that things are not as I learned in school. ...On paper there are certain rules to be kept. However, as due to financial matters*

Conclusion

The research above focused on ongoing changes in health care. However, all these points remain within the “illness-paradigm” despite the aims put forward in concepts of the ‘contemporary patient’. Today, when the contribution of health care to curing or saving a patient is 15-20% (according to estimates), taking factors other than the actual illness into consideration is (should be) essential. The inequalities of welfare, differences in lifestyles and ways of living, exposure to environmental harms are far more relevant in terms of people’s health and quality of life. At the same time, the question remains whether health care can, whether it is to penetrate various areas of life (society, economy, politics) and extend its authority and efficiency.[36] On the other hand, the contemporary health care system – in Hungary as well as in welfare states – is more and more burdened with the ambivalence of ministration/service. Its aim is to cure, save lives, as well as to serve more and more the needs of patients (as a market participant). That again leads us back to the social, economic and political context, i.e. the defencelessness of people with low status in terms of their bodies and health.

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of hospitals, as hospital do not really have money, or much money, tools need to be spared. It’s protective tools, rubber gloves, masks, hairnets, needles, syringes, etc. I don’t know what else to say, we have to be spare these, and we try to do avoid something bad to happen. But still, we cannot do it according to regulations, as described in the books.” (Nurse)

[36] Even by means of (bio)power, for the sake health protection.

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