doi: 10.3325/cmj.2010.51.365

Vanishing Act

By Nataša Škaričić

natasaska@yahoo.com

Branimir Glavaš, one of the most famous convicts of war crimes committed during the 1991-1995 war in Croatia, went on a hunger strike in 2007 while being held in the Zagreb Prison Hospital. This caused turmoil among the top government officials and provoked a strong reaction from the public: an intense debate raged for weeks among civic organizations, political parties, state justice, and health administration. All of them looked for the legal way to handle such delicate legal and political situation – should the hunger strike be treated as a political action, allowing it to continue even at the cost of Glavaš's life, or should it be treated as a behavior of a patient whose health is under the authority of a health institution (1).

I became a part of this debate by accident, during my appearance on the Croatian National Television for altogether different reasons. The host had me wait in the studio while Slobodan Lang, a physician and a member of the Scientific Council for Peace and Human Rights of the Croatian Academy of Sciences and Arts, defended the action of Branimir Glavaš, invoking the Declaration of Tokyo from 1975 and the Declaration of Malta from 1991. At the same time, Neven Ljubičić, Minister of Health and Social Welfare at that time, expressed his concerns about legal obligations of physicians faced with patients who refuse treatment in times when their lives are at stake. The biggest question was what the physicians may and can do if due to starvation Glavaš losses consciousness or capability to make decisions.

"This is defined by the Law on the Protection of Patients' Rights, the one we have had since 2004," I said. This was met by an awkward silence, making it obvious that they were simply not aware of or have forgotten that Croatia has a law that regulates rights and obligations of both physicians and patients regarding medical treatments and clinical trials, the law that should be used to solve dilemmas like the Glavaš case. No one commented on my statement.

Since medical institutions, according to the above Law, have the right to treat patients contrary to their wishes in cases when patients are at immediate risk of dying, my public appearance in the studio made a number of Glavaš's supporters seek me out and try to convince me that international conventions are above specific state laws. They did not relize that my only intention was to remind others of the existence of the Law, leaving the question of who outranks who to some judge who would get a terrible headache if the case ever reached court.

In any case, after three years of its existence the Law was not on anyone's mind, not even of those who passed it.

This bizarre episode encouraged me to carefully monitor when the Law is mentioned, used, and referred to in health reforms, other health laws, or public debates, as well as how the appointed supervisory boards function when it comes to enforcing the rights granted by the Law and what the opinions of patients using health services are. What do they know about their own rights? Dare they realize them? How do the health institutions and those working in them respond when patients demand the rights that are guaranteed by law?

With the support of SCOOP, a Danish network for investigative journalists in East and Southeastern Europe (http://i-scoop.org/), I conducted a journalistic investigation using documented stories of patients, surveys sent to members of local (county) Committees for Protection of Patients' Rights, and interviews with members of both civic organizations and national committees (2-4). Despite his initial promise, Darko Milinović, the current Minister of Health and Social Welfare, was not available for an interview to discuss my findings.

The results of my investigation were published in many media and interpreted as evidence of an unsuccessful Milinović's health reform but, sadly, none of the mainstream media reported even the basic conclusions of the research. Even though the research has never been aimed to reflect on the health reform or its consequences, the media conclusion is somewhat interesting. Until now, the health reforms (meaning the changes of the legislation on health insurance that occur every year in Croatia and for which the name health reform is usually used) have never mentioned the rights of patients with regard to modern medical ethics or liberalism granted in the Law. Patients' rights are, however, often used in the discussions about finances. It seems that no one understands that patient's rights must be treated as individual and not as social rights.

Since the biggest changes in the Croatian health system affect health insurance system regulated by the Health Insurance Law and the Supplementary Health Insurance Law; reforms occurring every year change, in one way or the other, the way health services are paid for, the number and the types of free services, the price of the supplementary health insurance provided by the state, the amount of participation for health services, and the number and types of insurance categories of those who do not pay participation. It is therefore evident that the public is being told that more money means more patients' rights, giving a completely wrong impression, one that has unfortunately already taken root in the public opinion.

Health administration, while reducing the amount of free health services on a yearly basis, still constantly advertises and emphasizes that the patient is in the center of its reforms. Therefore, it is no wonder that the media have concluded that my findings, which show how the rights of patients guaranteed by Law are not being realized, also point to the fiasco of Milinović's reform. This on its own demonstrates that the essential contents of the Law have not made it to the sphere of a wider debate, let alone a public consensus.

I will not list here the types and means of insurance law changes or analyze their repercussions, for they are vast and present another issue altogether.

What is completely ignored as a public topic are not only the rights of patients guaranteed by the Law but also the existence of a huge network of official bodies established to supervise the realizations of those rights, such as Committees for the Protection of Patients' Rights in each of 21 Croatian counties, as well as the National Committee for the Protection of Patients' Rights.

My research produced a number of disturbing findings about these bodies:

1. The committees, which are, according to article 33 of the Law, obliged to operate publicly, fail to do so – only 10 of 21 committees have responded to my survey, even though they were notified of its importance and the importance of cooperation with the media, both home and foreign, in which the results would be published. None of the committees had web-pages or separate phone lines, and the county web-pages also lacked information about the committee functions or about the committees themselves. The members of the committees had no official e-mails, some did not even use a cell phone. Finally, the reports of the National Committee's activities are not available on the web-pages of the Ministry of Health and Social Welfare, and the Law itself is not listed as one of the relevant legal acts at the official Ministry web-site (http://www.mzss.hr/hr/ministarstvo/zakonodavstvo).

2. The members of the National Committee are elected by discretion of the head officials of the Ministry, without public call for applications or any other legal procedures. The first chair was Petar Badovinac, who held the office from 2005 until his death in 2008. During his presidency, the meetings were held only to discuss the organization of the Committee's work. From 2008 until 2009, the Committee did not operate at all. In 2009, the Croatian State Secretary of the Ministry of Health and Social Welfare Drazen Jurković appointed Mrs Mensura Drazic as the chair of the Committee. Throughout all these years the Committee has not reported or solved a single case regarding severe violation of patients' rights.

3. Funds annually spent by the counties for the promotion of patients' rights or the work of the committees are mostly nonexistent or are sometimes listed as undefined payments for attending meetings. In 2009, Međimurje county spent HRK 19,800 (€2750) on "popularizing phone numbers of the committee" and printing leaflets and promotional materials. The City of Zagreb spent HRK 27,000 (€3750) on "dealing with complaints, public debates, reaction to press media, and monitoring health institutions" from October 1, 2008 until December 31, 2009. Split-Dalmatia county spends annually HRK 10,000 (€1390) for the work of the committee, Požega-Slavonia county spends annually HRK 9000 (€1250), while Sisak-Moslavina county has in the last 6 years spent HRK 60,000 (€8335) for the "promotion of patients' rights." Ten committees have spent just above HRK 100,000 (€13,900) in the last 5 years, while the National Committee, according to its current president Dražić, has spent resources only on the members' fees for attending the meetings. This, however, does not corre-

late with the official health budget for 2008, when minister Milinović started the health reform. The budget allocated HRK 10,000 (€1350) for "services", and HRK 70,000 (€9725) for "other undefined expenses." In 2009, when the health reform should have been implemented, the money allocated to this budget item increased to HRK 299,000 (€41,530) of which HRK 188,000 (€26110) was spent for the work of the committees and the rest on undefined expenses. In the health budget of 2010, there were no funds for the promotion of patients' rights. Since the Minster was not available for the interview I was not able to find out where these funds were reallocated to.

My investigation discovered other important anomalies:

1. None of the political parties in Croatia wanted to define patients' rights, including the former Coalition Government from 2000 to 2003, lead by the Social-Democratic Party (SDP), which declares that it is precisely their engagement with human rights that distinguishes them from the actual leading democratic Christian party Croatian Democratic Union (HDZ).The public, however, perceives SDP's liberal attitudes regarding rights of homosexuals, ethnic minorities, and reproduction rights as their only distinction from the governing party.

2. Two civil organizations, the Association of Croatian Patients (ACP) and the Croatian Association for the Promotion of Patients' Rights (CAPPR), function in surprisingly unfavorable conditions: ACP has never had any funds for its actions, while CAPPR this year did not receive any of the funds the Ministry allocates to civic organizations.

3. The scientific community has almost no interest in the topic of patients' rights: two research studies have been conducted so far, both on a modest sample, one in 2004 by the CAPPR (5) and the other in 2006 by a research group led by an anesthesiologist from Split, Dr Marko Jukić (6). The latter study showed that 34% of physicians were not aware of the existence of the Law of Protection of Patients' Rights, while 45% were unaware of the existence of an informed consent form; 33% specialists of internal medicine and only 16% of anesthesiologists reported that they provided detailed information about the treatment plan and diagnostic procedures to their patients. The authors concluded that physicians were not formally educated about patients' rights. The study from 2004 showed that not even a single physician or a single patient were able to list any of patients' rights and that 35% of psychiatric and 31% of non-psychiatric patients thought that physicians had the right to deny information about the patients' condition. In addition, 67% of psychiatric and 58% of non-psychiatric patients did not give consent for surgical procedures, 65% of psychiatric and 76% of non-psychiatric patients reported not being able to access information about their health insurance, while 45% of physicians viewed patients' rights as a threat to their own rights.

4. Patients reported that health institutions and medical personnel, even in cases of clear violation of patients' rights liable to legal actions, had no interest to act based upon the law, not even to reduce the damages incurred. For example, when a case of negligent treatment is established, a hospital may refuse to provide relevant medical documentation to the patient (7).

All these findings only confirm the perception of the general public that the health system works without patients and that it works without a universal concept of involved patient care.

We should also consider the principle of availability of health services to all, defined by the article 5 of the Law. This fundamental right not only guarantees the same treatment to all citizens, but is also meant to help fight corruption and discourage illegal acquisition of those rights. However, it is impossible today to say anything about the status of that particular right when it comes to Croatian citizens: any attempt of the health administration to force public health institutions to keep transparent and up-to-date waiting lists on their web-pages has failed. For example, the waiting lists of the largest and most prestigious hospital center in Croatia, University of Zagreb Hospital Center, have one or even no patient listed, although the waiting time is from several weeks to several months. This shows that a fundamental patients' right, guaranteed even by the constitution of Croatia, is neither applied nor monitored, so it is logical that the other "more sophisticated" and "advanced" rights never make it to the center stage of politicians or medical professionals' debates.

Is it too much to claim that the health system which does not recognize or acknowledge patients' rights, backed up by the administration that fails to implement its own laws and by the public that is uninformed and incapable of realizing their rights, is an inefficient and anarchistic system? I think not. Even less consideration should be given to health reforms on which every year enormous amounts of money are being spent (HRK 18,000,000 or €250,000 last year), the purpose of which is to maintain a never changing system that is difficult to take part in, both for the medical personal and patients. My investigation has shown that not only have we not improved but we do not even want to make a single step in that direction.

The marginalization of this subject likewise leads to misinformation provided to other countries in the EU: according to the Euro Health Consumer Index, Croatia ranked the 29th out of 31 countries in 2008 (8). Yet the following year, it moved up 7 places, and the reasons given were improved patients' rights and health informatization (9). Since this evaluation is unrealistic as shown by my investigation, one can assume it was based on official reports from those for whom this is of "political" interest. In other words, the system is crying out for data that would be accurate and based on evidence, data capable of forcing the health administration to reflect on its actions and change its future policies.

References

1 Jureško G. Let Glavaš die? [in Croatian]. Available from: http://www.jutarnji.hr/pustiti-glavasa-da-umre-/237697/. Accessed: August 3, 2010.

2 Škaričić N. Croatia, country with no patients' rights [in Croatian]. Available from: http://www.e-novine.com/drustvo/39075-Hrvatska-zemlja-bez-prava-bolesnika.html. Accessed: August 3, 2010.

3 Editorial. All diseases of the Croatian health system [in Croatian]. Available from: http://www.h-alter.org/vijesti/hrvatska/sve-bolesti-hrvatskog-zdravstva. Accessed: August 3, 2010.

4 Škaričić N. Six years of HDZ's Law on the Protection of Patients' Rights [in Croatian]. Available from: http://www.tportal.hr/vijesti/hrvatska/76256/sest-godina-HDZ-ovog-Zakona-o-zastiti-prava-pacijenata.html. Accessed: August 3, 2010.

5 Rušinović-Sunara Đ, Lugović G, Biserka B, Radovančević Lj, Liović J. Responses of patients and healthcare workers in Croatia on the Bill on Rights, Obligations, and Responsibilities of Patients in Croatia, pilot-study [in Croatian]. Medix. 2004;10:162-6. Available from: http://www.pravapacijenata.hr/pdf/Stradovi/OdgovoriPacijenata.pdf. Accessed: August 3, 2010.

6 Jukic M, Kvolik S, Kardum G, Kozina S, Tomic Juraga A. Knowledge and practices of obtaining informed consent for medical procedures among specialist physicians: questionnaire study in 6 Croatian hospitals. Croat Med J. 2009;50:567-74.

7 Škaričić N. Desperate struggle for the truth about Dominik [in Croatian]. Available from: http://www.tportal.hr/vijesti/hrvatska/67453/Trogodisnja-ocajnicka-borba-za-istinu-o-Dominiku.html. Accessed: August 3, 2010.

8 Health Consumer Powerhouse. Press release: Croatia ranked lowest according to Eurohealth consumer index [in Croatian]. Bruxelles, 13 November 2008. Available from: http://www.healthpowerhouse.com/files/2008-EHCI/pr/Croatia%202008%20EHCI_translation.pdf. Accessed: August 3, 2010.

9 Health Consumer Powerhouse. Press release: Croatia spectacularly improved its Eurohealth consumer index [in Croatian]. Bruxelles, 28 September 2009. Available at: http://www.healthpowerhouse.com/files/Croatia.pdf. Accessed: August 3, 2010.