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## **MOURNING FOR TOMORROW – HOPE AND HOPELESSNESS IN ONCOLOGY WARDS IN SERBIA**

**ABSTRACT** This paper is designed to show how the space of the clinic powerfully shapes the relationships between oncology patients and their doctors as well as how it informs the relationships between patients themselves. It illustrates how historically particular ideas about citizenship and the role of the state in a postsocialist context of contemporary Serbia produce specific ways through which hoping and hopelessness are manifested. In the space of the clinic the patients' subjectivities and state hierarchies are amplified by constant engagement with the urgency of decision making, and the immediacy of decay and suffering. Negotiation for possibilities of treatment through the interactions with doctors and medical institutions as fetishized extensions of the state creates distinct strategies deployed by oncology patients to understand one's future and one's place in the space of the clinic.

It is the goal of this project to pursue a deeper understanding of how the haunting manifestation of fear of the possibility which future brings shapes patients' understanding of daily living. Unraveling the narratives about illness, fears and expectations of oncology patients in Serbia will lead to grasping their ideas of what it means to be alive in the characteristic context of postsocialist oncology wards in Serbia.

**Key words:** postsocialism, oncology, hope, suffering, illness, expectations, future, state, citizenship

### **INTRODUCTION**

**T**his paper, based on ethnographic fieldwork conducted during the summer of 2014 in two major oncology clinics in Serbia, will delve into an analysis of socialist practices, still present in the expectations and everyday lives of oncology patients, with the goal of discerning how the remnants of Yugoslav

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socialism can be understood as a dynamic component of postsocialist Serbia, and the conceptions of the capitalist future. This approach moves towards asking how socialist and postsocialist practices can be theoretically interpreted in a way that acknowledges their continuity with contemporary efforts to create a new, democratic, neoliberal state. It examines how the relationships between doctors and their patients mutually shape understandings of illness and healing as well as experiences of hope and hopelessness for oncology patients in contemporary Serbia. In so doing, this paper illustrates how ideas about citizenship, subjectivity, and the state are understood and exercised in relationships between oncology patients and their doctors as they negotiate responsibility for care and for health. I argue that the historically specific ways the state power was exercised during the Socialist Federative Republic of Yugoslavia informs the existing patients' understandings of doctors' roles and responsibilities. Furthermore, I suggest that ideas oncology patients have about their relationships with doctors inform the understanding of their potential future, and the outcome of their medical treatment. My informants' expectations of the state are transposed to their expectations of their own future. Their hopes are placed in the hands of their doctors, and are also in a great measure shaped by their daily interactions with other patients.

This paper aims to illuminate the ways in which exchanges between state and citizens mediated through medical systems as the imagined and fetishized extension of state authority produce the narrative of what it means to be an oncology patient negotiating possibilities for medical treatment in Serbia.

I suggest that specific forms through which state power was exercised during the socialist era of Yugoslav history produced a sense of equality, solidarity and belonging (for the purpose of this paper I will not engage with questioning how illusory that sense might be). I believe that this production of specific forms of citizenship has greatly influenced the ways in which medical citizenship is created in the context of postsocialist Serbia. Additionally, the patients' assumptions of the unified experiences of getting treatment at these two clinics created fruitful ground for the emergence of unified expectations of the future. More specifically, I suggest that assumed equality in access to health care forms an imagery of the universal experience of illness and healing. This, furthermore, opens up a space for mutual identification of patients with one

another as they observe each others' experiences on a daily basis. Encountering pain, decay, healing or dying allows for universal narratives of hope and hopelessness. These narratives are influenced by the specific spatial and bodily circumstances in which my informants are receiving their treatment. But, at the same time, their bodily and spatial experiences are not occurring in an apolitical vacuum. Their interpretations of the encounters with the bodily manifestations of illness are informed by the ideas about the healthy body, their role as workers, which I will address later, as well as by their imagination of the unified experience when encountering the medical discourse in Serbia. I argue that in order to understand the ways in which medical space shapes the imagination of the future for oncology patients, we must take into account the historical context in which they, as citizens of Serbia, initially imagine their relationship with their doctors and medical institutions. To do this, I will examine two of the most common tropes used in the stories my informants shared – the trope of doctors as heroes and guardians, and the trope of loss.

## **HISTORICAL CONTEXT**

VMA (Military Medical Academy) is a medical clinic with a relatively long history on the territory of Belgrade. Established in 1844, as a legacy of monarchist Serbia, it was changing structure and location during the period of the Kingdom of Yugoslavia, and later the Yugoslav socialist regime. For the greater part of its existence VMA operated under military protectorate and with its financial support. After 2007 VMA extended its services to all citizens of Serbia, not only to military families. Kamenica, another site where I conducted research, is a medical institute in Vojvodina (an autonomous region of Serbia) and is referred to, by the patients of Kamenica, as the medical jewel of Serbia. These two clinics, with oncology wards embedded in their structure, have been shown to be the preferred treatment venues for those diagnosed with a serious, malignant condition. Since this paper will mostly deal with issues of responsibility, expectations, resignation and “letting go”, the reputation of these clinics is important in order to understand the reasoning behind the initial struggle to get admitted to one of these, and the subsequent giving up on the struggle itself.

Existing scholarship on the space of the “Balkan” often focuses on the unstable, blurry national and ethnic identities that shape current understanding of boundaries and borders as unsettled and volatile (Jansen 2006; Mazower 2007). Additionally, ethnic and national tensions along with the turbulent past, nesting orientalisms and balkanisation (Bakic Hayden 2006), colloquially implied by the history of the region, have been used as theoretical frameworks for understanding the unique political development of Yugoslavia. More specifically, Yugoslav socialism is understood as an atypical example within the socialist history of the Eastern Bloc (Lydall 1984; Judah 2009; West 1994; Woodward 1995). I will argue that the turbulent history and its effects on citizens of Serbia have culminated in a complicated interdependence between the socialist legacy and the emerging capitalist expectations placed on the citizens. It is important to keep in mind that the private sector in medicine and global pharmaceutical research coexist with the public health care system and configure the newly emerging practices of medicine in Serbia.

The complicated and turbulent past of the last several decades has continued to haunt the everyday existence of Serbian people. I would argue that, rather than only producing unstable ethnic and national identities, the troubled past of Serbian people has produced a complicated set of expectations between state and its citizens. Citizens have adopted the strategy of placing the glory, and later the blame, on those in the position of authority. After the monarchy, and after World War II, Tito (Marshal Josip Broz) was *the savior*. After the fall of Yugoslavia, Milosevic, the president of Serbia, took on the same role. Kostunica and Boris Tadic did the same after him. The rhetoric of ending the corruption and leading the country to a *better tomorrow* was often deployed. The transitional period in Eastern Europe, and the postsocialist environment, is colored by the ideology of saviors and those *who destroyed us* (Burawoy and Verdery 1999). Similarly, in Serbia, the political tensions against the current regime were often formulated against the current government (for example: “He is finished!” – 2000 campaign slogan of the Democratic Party in Serbia aimed against Slobodan Milosevic, President at the time). The authority assumes both roles (that of a savior or a destroyer) depending on when in the history of socialism and transition those roles were imagined. But, what is critical is that the citizens are not active in these formulations, but passive – they are *saved*, or they are *betrayed*. In a post-socialist context, with a complex history of power and authority (Maksimovic

1965; Verdery 1996) the emergence of possibilities and responsibilities for choice making, can at the same time be an aim and a burden not only for citizens more broadly, but also for medical patients. The way that responsibility for decision making is located and experienced by patients and their doctors has direct bearing on questions regarding the changing medical practices and the tensions between socialist assumptions about the patient's (or citizen's) role and post-socialist expectations created by the emergence of new medical practices.

I will use the interviews which I conducted during the summer of 2014 in Serbia to show how oncology patients in two major public clinics (VMA and Kamenica) experience their own role in the processes of diagnosis, participation in clinical trials, decision making regarding their own treatment and lastly, their participation in my own anthropological research. I will also occasionally draw on my own experience, since my father died a little more than two years ago and I interacted with medical institutions in Serbia for four and a half years, gaining plenty of experience on how negotiating skills come in handy when dealing with the post-socialist bureaucracy.

Additionally, it is important to note that the patients I have had a chance to talk to are mainly in their 40s and 50s. They have lived through the most difficult times in the recent history of Serbia. They grew up during years of social welfare, stability and international recognition of the strength of the Yugoslav nation. In the decades that followed they witnessed, suffered or actively engaged in the division of the Yugoslav nation. They experienced the economic crash of the 1990s and the inflation, various forms of sanctions and embargo from 1992 to 1996, the NATO bombing in 1999, the creation of independent Kosovo in 2008, and all the traumas in between.

The *state of exception* (Agamben 1998) and the urgency of daily life have been internalized for these generations. The authority has been in charge of making urgent decisions for a very long time, and the *now* has experientially been a space between one horrific event and the next, such that the agency of citizens of Serbia has always been in suspension.

## DOCTOR AS A HERO

In order to be allowed to contact patients for interviews I had to go through the ethics boards and committees of the two institutions. After that, I was introduced to patients by their doctors and initiated conversations when nurses and doctors were not around. I asked them whether they would be interested in talking to me, told them why I was interested in their experiences and gave a spiel about the voluntary nature of participation. But I was surprised to find that patients would usually stop me half way through, not out of confusion or the need for clarification but with statements such as *“Do not waste my time. If you want to talk to me, talk to me. I do not want to hear about all those things. Ask me what you want me to tell you.”* Initially, I struggled; I wanted to do the research as I thought I should. Their behavior could be interpreted as impatience and a desire not to lose time on the insignificant details. But, those pieces of information were insignificant for them for specific reasons, and I suggest that statements that I heard, similar to: *“Look, did VMA let you here? Did they ask why you are here? Well, that is good enough for me,”* or similar iterations of the same attitude, gesture towards the trust they have in Kamenica and VMA. I did not expect the lack of interest for my background: was it really enough that Kamenica and VMA cleared me? What if the view of these institutions does not coincide with the patients’ views? What if they feel pressure to talk to me? I tried asking them to have conversations outside of the hospital. This produced far more discomfort and unease than I anticipated. I could either talk with them, there, on their territory, or the territory they felt protected on as I later imagined it, or not at all. I was afraid that I would not get the needed material – the complaints and the personal experiences. But, surprisingly, I heard open and elaborate praises for the doctors but hatred towards the current state. The clinic was a safe place to share thoughts. Additionally, the doctors (regardless of the kind of care they provided) were understood to be helpful, and “miraculous” where, at the same time, the newly emerging capitalist state was failing them.

I realized I came there with the assumption that my fieldwork would unfold by my rules, or, rather, the adopted rules of a Western educational institution. I was discouraged rather early – the research, it seemed, would happen according to the rules of the clinic, under its protectorate and control,

through the spatial control of the state disguised as medical institution. These rules were not vocalized; I was allowed to initiate conversation with the patients and lead the conversation in various directions. But, the patients' need to stay in the clinic speaks of something far more complex. In his discussion of the panopticon, Foucault (1977) addresses various governing practices which result in the modification and correction of behavior based on imagined or material surveillance. But, what I argue is taking place in VMA and Kamenica between doctors and their patients is something that expands on the panopticism. I suggest that it might be useful to look at the behavior of my informants as indicative of an internalized need for the Panopticon project. Their need to stay in the clinic, rather than meeting outside of it and by their own rules, time and dynamics is indicative of the safety and comfort they felt inside the space of the hospital. The white coat I wore was not interpreted as a barrier for the conversation – it was a bridge for sharing experience. I argue that the Yugoslav socialist regime cultivated a sense of security and protection which influences the ways in which state institutions are interpreted in contemporary Serbia.

During an interview with the ethics committee I was asked why I would need to talk to patients outside the clinic in a neutral environment, as I saw it - and was told that this “will not fly” with the patients. And it did not. Patients expressed the desire to talk at the clinic, and gave me their schedules so I could find them again if I wanted to. The white coat I had to wear while at the clinic did not make me a threat or someone they did not want to open up to – it actually made me safe to talk to. I was not part of an American conspiracy (something many patients brought up in our conversations), I could not have been since I was “cleared” by the VMA and Kamenica.

Moreover, soon I was referred to by the community of patients as “the girl who is there to help”. I was there to help improve the conditions for treatments, to appeal for more money, to generally “help”. My attempts to describe my role were ignored; I was told what my role was. This narrative emerged from the patients' interactions among themselves – I was introduced by the doctors as a student who is doing research for her PhD studies in the US.

My informants talk about their doctors in a similar manner. Their doctors are “rushed”, “overwhelmed”, “and too busy”. When they talk about their doctors they share their gratitude for their time – whatever that time may be. They actually sound rather apologetic on behalf of their doctors: *“Oh, well given the resources they have, they are doing their best.”* Many of my informants spoke of the moment of realizing that they obtained a referral to receive treatment at VMA as a moment of relief. I spent a fair amount of effort during our interviews asking them to describe the ways in which they got their information about their diagnosis and treatment. I wanted to hear how the conversations about what it means to start chemotherapy were orchestrated and how they felt about asking questions about the whole process. Many simply said that they got the diagnosis and “that is it”. Marko, a retired military officer said: *“Well, I did tons of tests. Finally, after three months, the doctor set me down, said: You’ve got this and this, and we will do this and this. There was not much philosophy in it.”* Or, as phrased by my other interlocutors: *“What do you mean where I get the info? Why would I need info? Isn’t that his job?”*

It became clear that there was a polarized dichotomy between the healers and the healed. The alleged need for informing the patient, for his or hers participation in decision making was not working under the same assumption which created the need for voluntary nature of participation and treatment (again, in most global pharmaceutical practices), as well as in taking part in pharmaceutical research and the institution of informed consent.

Patients are relieved when referred to VMA, they feel “as if they are already healthy”. In this way, magical and fetishist components are ascribed to the medical institution. The state becomes saturated with power in the imagery of oncology patients, and this fetishized power of the state (Taussig 1997) is mediated through medical institutions and its doctors. One of my patients talked about the history of this institution and the Balkan region as being the rationale for his unquestioned trust towards the doctors at the VMA:

*”You are young, you do not know. Today’s generations do not remember. But, these doctors are the best in the world. Why? Well, they did what no one did, they saved our soldiers, and they worked with nothing. They saved thousands.*



*During sanctions, they had no medications, no instruments, it was all old and broken. If THEY cannot save me, no one can.”*

It was clear that the hope was placed solely in the hands of the doctors in charge of his treatment, and he would not have chosen any other hands. These hands were not the best for handling his treatment because they were the most medically educated, or equipped with state of the art medical resources. These hands had dealt with the *state of exception* (Agamben 2005), and had, allegedly, restored the state’s stability. The imagery of my informants implies the understanding that someone who can protect the state and its citizens will be able to perform any miracle with regards to their medical treatment.

The transition of Eastern European countries is a process which is a part of a much larger transition - from Fordism to flexible (or neoliberal) capitalism. Elizabeth Dunn in *Privatizing Poland*, shows how the transition itself should be analyzed as a complex nexus of sophisticated forms of economic and state practices. Influenced by various forms of socialisms and the imagined “omnipresent” idea of what Capitalism is. She explains how personhood in the context of capitalism stands on the idea of individual responsibility for one’s well-being. A worker is responsible for his success or his failure in the market. The state has little if anything to do with his competitiveness in the market. She adds,

”Polish workers, however, have a stronger standpoint from which to criticize these changes in the management and in personhood, because the shift in governmentality is not total. Polish workers spent more than forty years under socialism, which organized both production and personhood in very different ways” (Dunn 2004, 7).

I argue that this specifically created worker identity reflects a broader mechanism of personhood making. Even though Poland and Serbia followed different trajectories of development, they share some of the same circumstances. Serbia, like Poland, was reformed as a modern country in the years after World War II. The socialist regime was in power up until the 1990s, or the fall of Yugoslavia. Capitalism is imagined both as a goal to be achieved and a frightening future when citizens will be left without the state protection.

The identity of the work force can be compared with the identity of medical patients, particularly in the political context in which Serbian oncology patients found themselves. In a communist ideology and socialist reality, worker identity was an all-encompassing ideology. The discursive practices produced the ideology of the citizen/worker dichotomy – the proletariat was the core of society. In a similar manner, becoming a cancer patient is an identity that encompasses flows through all other identities of the person. Bodily manifestations find their way into other realms of existence and greatly influence the remaking of oneself in the newly emerging chaos of being sick.

Several interviews I conducted with physicians focused on communicating a terminal diagnosis to terminal patients. One of the doctors I talked to, a Bosnian ex-military doctor with good reputation, told me how he experienced the change in the medical system and policies regarding discussing the diagnosis with the patient. He said that the practice of telling the patient exactly what is wrong began to emerge during the 1990s and is still developing. He said that when he first became a physician (during the mid-80s of the 20<sup>th</sup> century) the popular practice was to tell a slightly modified version of the “truth”. Those with a terminal diagnosis would be sent home and the family would be given abstract and symbolic advice on how to make the ill person feel better. He says that it was up to the doctor to evaluate which patient “was fit enough to deal with the truth”. This practice reflects a paternalistic relationship between patients and their doctors. The patient is not only treated by the doctor – the doctor also, of his or her own accord, makes decisions on behalf of the patients and their families.

I distinctly remember a situation when my parents discussed the next step in my father’s treatment. My mother was working on a list of questions for the doctor: what should my father eat, how, is there a different kind of treatment, is this or that hospital better or worse, what are my father’s prospects when it comes to life expectancy, chances of survival during surgery and so on. My father was clearly agitated by this, but not necessarily because of the pressure he might have felt. His comments were directed towards her being annoying and “bothering the doctor; he knows what to do, why ask around...” This situation, in the light of the interviews I conducted two years later, can be interpreted in two ways. My father felt like it was not his place to interfere

with the strategy which his doctor was developing for his treatment. His response could have been a result of his complete faith in the ability of his doctor. On the other hand, it might have been the fear that his, or his wife's nosiness could be interpreted as questioning someone's ability to perform their job. This could potentially result in not getting the best care possible, after offending the doctor. I suspect that the meaning of this behavior lies somewhere in-between.

Either way, these examples speak of the possibility of a paternalistic relationship between doctors and patients that prevailed during the rise of Yugoslavia. Oncology patients in Kamenica and VMA often addressed the narrative of the loss of the mentioned paternalistic relationship with a lamentation, phrased almost always in the same way: "We do not have a state anymore". This indicates that once there was a state (former SFRY is usually implied by this), one that could help the citizens, and now that is no longer the case.

Another doctor, this time from Kamenica, when asked to talk about her strategies for dealing with sensitive situations of terminal diagnosis, gave a similar response. She is a young doctor, in her early 30s and was definitely not working during the 1990s, when the alleged shift in practice started to emerge. Yet, she describes the conversations she has had with patients and family members in a similar manner as the other doctor. She drew on a rhetoric of "being in the position to decide" which information should be said and to whom. She said that there are many situations in which it is quite clear that someone has a month or two to live. At that time, she rarely decides to tell the patient that she suggests stopping the treatment. She rather phrases it as: *"It might be best to listen to your body for a while. Your results are getting worse. The best strategy would be to take some rest, a few months maybe and then we take it from there."* When I asked her why she wouldn't tell them what is happening to prepare them, she responded: *"That would be cruel."* Her reasoning was that the patient *cannot handle* the truth, which is a rationale used worldwide historically when dealing with terminal illness. This alleged inability to handle the truth is exemplary of a broader narrative about doctors not only being the healers but at the same time being the "guardians" of those less able to take care of themselves.

This narrative of patients being passive recipients of care is produced and perpetuated through the interactions between doctors and patients. Both doctors and patients take part in the production of a post socialist discourse of what it means to be a good citizen and what it means to be a good worker. From the doctor's point of view, being in charge creates a certain level of responsibility – the choice of what to do, how, and who is given the information about what is done. On the other hand, patients are often reluctant to make a decision. For example, doctors with whom I had a chance to discuss the agreement to begin chemo and how that process usually goes from their experience, had a lot to say about the expectations placed on them by patients. One of the doctors I talked to, a 40-year-old Serbian practitioner – gossiped about behind his back for being “full of himself” – talked about presenting the choice to the patient. He shared that many patients ask him what to do when faced with a diagnosis of a serious and life threatening condition. The fear of the diagnosis, as well as an implied acknowledgment of the scientific authority can in great measure shape the ways in which oncology doctors are placed in the position to make decisions. This is in no case completely emblematic of socialist, or postsocialist medical practices in Serbia. But, it is important to note that the acceptance of that responsibility on behalf of oncology doctors, or its deferral to family members or a counselor speaks to the crucial difference that gestures towards the specific socialist history of Serbian context. This difference is situated in the ways in which doctors in different historic-geographical contexts exercise the responsibility placed on them.

The doctor I have talked to says that he suggests the best course of treatment according to his opinion, which patients mainly choose to accept. He explained that refusal of a conventional treatment requires signing an informed consent – one in which the patient acknowledges that the treatment has been offered and he or she refuses it with full understanding of the implications of such an act. It is interesting to note that in most cases the refusal of therapy has to be signed, which is usually not the case with the acceptance of the therapy. The standard, expected course of events suggests that in postsocialist Serbia compliance and acceptance of the suggested treatment is the norm; negotiation, refusal, second opinions are not expected. This is a moment which is indicative of the assumed authority of the medical system – refusal of the standard treatment can be problematic, and requires further contemplation and full understanding.

Informed consent, in the Western Europe and USA context is required with the acceptance of a difficult and challenging procedure or treatment. In Serbian context, as I have said, it is quite different. The doctor I have talked to said, *“Those who do not accept the treatment, those people are primitive. Very often they come back a few days later asking to start the suggested treatment. It would be insane of them not to accept.”*

This particular statement speaks of a complicated issue regarding the medical practice of oncology wards in Serbia. The binary choice of accepting or refusing the treatment has been reduced to only one good choice. Only those who choose to deal with the illness in the expected way are considered to be “sane”. They are making the right choice. Those who refuse treatment are not demonstrating their expected rational way of thinking, so their decision-making capacity must be impaired – they are “primitive”. Also, it can be useful to think about making the right choice as actually following the invisible guidance of the state. It means to be a good, obedient citizen.

In Kamenica, when I had a chance to talk to a young man, in his early 20s and his mother, I discovered how the fear of authority and deferral of responsibility gets transferred from one generation to another. This young boy, of Roma ethnicity, received therapy in the presence of his mother. They were, as his doctor told me “gastarbajteri” – people who worked in other European countries, earned fast cash and came back to Serbia to spend it.

The doctor, without any initiative on my part, told me, *“His mother, she constantly has questions. Oh, Gypsy business you know!”* This last sentence was a rhetorical one. “Gypsy” is a derogatory term in Serbia, used to describe Roma populations, and the idiom “gypsy business” means something petty, filthy, and undignified.

It was *undignified* of this woman to ask about her son’s condition. This can be related back to my father’s potential frustration with his wife’s need to form a list of question – it could be interpreted as undignified to ask, to show interest, rather than to simply obey.

During the 1990s there was an increased popularity of private clinics. But, interestingly, even though the urgency for private care and what it implies is more needed by the oncology patients than anyone else, they are the ones who benefit the least from the emergence of the private sector. To be more specific, oncology treatment in public institutions in Serbia implies long wait times for testing, scheduling therapies, checkups or operations. Private health care is mostly advertised as offering services with little to no wait times, which is most alluring to those who might be counting the days they have left. But, given the economic means of the majority of Serbian citizens, private oncology services (which are among the most expensive services offered by private clinics) are out of reach for them. They can afford an occasional blood draw or swab, which only allows them not to wait a few hours in a testing room. But the advance testing definitely does not get them treatment any sooner. Patients, for the most part, are not in the position to take advantage of the private services they need the most. Their worries are not about the quality of the treatment but rather the urgency of it, and the impossibility of following the *advised* course of treatment. This advised course of treatment consists of a narrative produced by the patients' access to new informational technologies, their familiarity with the cutting edge trends in Western Europe, and the long wait times for checkups, treatments, scanning etc. Patients' position is neither here nor there – they cling onto the imagined opportunities of socialist medical systems of the past, which are no longer the same; they imagine the West as being full of opportunities – but what they see of it is a reminder of what they do not have. They believe that there is a better treatment out there for them – but they are stuck in the in-between space of postsocialist transition.

This situation informs the creation of a rather complicated understanding of socialism – democracy (capitalism) transition. What my informants experience of capitalism is only temptation, a reminder of what they cannot currently have as well as the fear that those things will remain economically unavailable to them with the ongoing transition towards capitalist Serbia. On the other side, the socialist legacy is the only thing they can turn to. Its position of authority is actually reestablished through the emergence of the private clinics. State, VMA and oncology doctors are their only guardians and they place all their hope in the hands of their healers.

## LOSS OF LIFE – LOSS OF HOPE

On the other hand, many of my informants spoke about “knowing what was coming”, implying that their death is inevitable. They sometimes even explicitly said that they have no hope and that their only aspiration is to feel no pain. One of the oncology patients, whose condition I had a chance to watch for several years, specifically said to his family members: *“I have made my peace with this. I cannot help you do the same, you have to do it on your own. Every day I can feed myself and do not feel pain I count as a stolen one.”* Janko already felt as if the life he was living at the time was not his; he had already lost his life, had already mourned it and felt that the days he lived without pain are not his own.

”I’d already had a presentiment of this state. In this cell, I felt life leaving me. Earthly things no longer mattered; bodily functions faded away. Even hunger tormented me less. I felt a strange sweetness. I just didn’t have the strength to get off my cot, and if I did, I had to lean on the walls to make it to the bucket... Wlodzimierz Borkowski” (Agamben 2002, 167)

Cancer patients are often experienced by others, as well as by themselves, as existing in the boundary between both acute and chronic condition. Their malignancies are often referred to as a “current” condition, a strategy deployed by oncology doctors I have had a chance to interact with. The “it would be cruel to tell them” is used almost as a mantra to justify the limited flow of information from doctors to patients at times of the rapid development of malignancy. On the other hand, patients more often than not talk about their condition as being a chronic one – a condition which will be with them until their end, which is not unimaginably far for most of them. At the same time the narrative of illness takes two rather different routes – one of a complete identification with the disease itself, and another, which emerges in conversations between patients and their families: a denial of any kind of influence of the illness on the patient’s personhood. Additionally, focusing on the clinic in a postsocialist context as a space in which medical citizenship is manifested, exercised, transformed and informed by medical practices, is important because interactions between patients themselves, and their interactions with medical staff, as concrete representations of the

state, powerfully shape emerging imaginaries of illness and trajectories for the future (Langford 1995; Livingston 2012; Wailoo 2011). Additionally, cancer produces particular narratives and imaginative connotations about personhood (Jain 2013; Sontag 1978). Ideas about the body and the self are always already shaped by institutions, practices and ideologies (Lock and Farquhar 2007).

Moreover, the space of the clinic and witnessing pain influences the way in which patients think about themselves in the context of anticipated death. A rupture in the continuity between the present self and the future self occurs and one of those is lost:

”When we lose certain people, or when we are dispossessed from a place, or a community, we may simply feel that we are undergoing something temporary, that mourning will be over and some restoration of prior order will be achieved. But maybe when we undergo what we do, something about who we are is revealed, something that delineates the ties we have to others, that shows us that these ties constitute what we are, ties or bonds that compose us. It is not as if an ‘I’ exists independently over here and then simply loses a ‘you’ over there, especially if the attachment to ‘you’ is part of what composes who ‘I’ am. If I lose you, under these conditions, then I not only mourn the loss, but I become inscrutable to myself. Who ‘am’ I, without you? When we lose some of these ties by which we are constituted, we do not know who we are or what to do. On one level, I think I have lost ‘you’ only to discover that ‘I’ have gone missing as well” (Butler 2003, 12).

The oncology patients I had a chance to talk to implicitly refer to the “future pasts” of their roommates (as well to the immediate pasts of some of them) as an always absent horizon of possibilities and an inevitable, but unspoken, certainty of their future. They are in a position of losing their future selves. The temporality of their state of dispossession is experientially not temporal – the prior order will not get restored. The witnessing of repetitive practices of body decay, sometimes healing or, more often, spiraling into the expected course of malignancy, and identifying with those who are suffering, are produced in a spatial setting of oncology wards. Losing the possibility of oneself in the future, forms a rupture and discontinuity in the present self and creates a space for the mourning of the future loss. By allowing for the dissolution between



now and tomorrow, the daily routine of witnessing slow and expected death produces the unspoken haunting of today by the ghosts of future.

Dragan, an informant of mine, after being asked to describe the ways in which his daily routine is affected and changed by going to the hospital and the diagnosis, said: *“I am not changing anything. Because I know how it will all end, I am not interested in changing anything.”* “What do you mean by that?” I asked. He laughed as if I had to have known what he implied by those words.

Further in the conversation Dragan said: *“My wife wants me to try different things... alternative medicine.”* He talked with a bored voice and resignation. “How does that make you feel, is it a burden?” *“Nothing is a burden any more. Even death is not a burden.”* After some time he started talking about how he failed raising his children and how he did not know how to raise them to be “honest, decent” people. “Do you think about it? Does it affect you somehow?” *“Nothing affects me anymore.”* Dragan, like many other informants, implied that there is an expected, certain outcome of his illness. They talked about “knowing how things go”, but never uttering what that means. They refer to the attempts of their families to participate in the treatment as a futile effort to avoid the inevitable. But they do not find the courage to vocalize their mild annoyance or destroy their families’ hopes. Their own hope, when it is mentioned – is long gone.

The loss oncology patients experience is an intangible one. They have lost the potential of their future. But, I argue that this loss of potentiality is not solely actualized individually and is also not placed in one material (or immaterial) origin of loss. Patients of Kamenica and VMA spend their therapy time in rooms of 6 and sometimes 8. These rooms are relatively small, and beds are placed rather close; two visitors cannot sit in between two beds. Every conversation is overheard by other people in the room. At night they hear each other moan, get up to go to the bathroom, ask for help when doing it, and they often spend restless hours talking about their illness and struggles. They do not bear witness to their own death but they bear witness to the deaths of those whose experiences they identify with their own. I have been asked to have group interviews by my informants – they felt as if they shared a narrative of healing and being in pain. And yet, they, in my eyes, had

rather different experiences. They were of different age, different education, some of them were single and alone, some had more than one child taking care of them. But the space, and the illness informed their attitude towards their experiences as being the same.

It was the state apparatus that was in charge of them that was the same, as were the temptation and inaccessibility of private clinics. They ate the same food, and lay in the same kind of bed. And occasionally, they watched one of them dying. I observed a conversation between two women, one of whom started therapy just one day after the other, and was just unpacking her toiletries. She asked the others in the room where the occupant of the empty bed was. They responded that she had been feeling ill the last few days and had died the previous night; the bed had just been cleaned. A moment of nothing, a nod, then a very quiet sigh and the conversation moved on. It was an event in a series of expected events for these patients. There is a specific form of certainty which is a continuation of the certainty of socialism these patients experienced. In the socialist work force they did not know how much money they would have, or what country they would live in when they woke up (inflation, civil war and embargo can do that to a citizen of a country), but they knew that their job would be the same tomorrow and that all they needed to do was show up. Similarly, oncology patients do not know how their treatment will develop, and often think that the inevitable outcome is their own death, but that their duty is to show up, be stoic about the chemo and to listen to what to do. As long as there is consistency, routine, source of instructions (their doctors) and a route to follow there is security.

The interviews I conducted with oncology patients showed me that repetitive exposure to others who share their diagnosis but are in different stages of metastasized cancer greatly influences the ways in which these informants talk about and experience their future. Bearing witness to pain, to the inability to take initiative and the expectations to be taken care of, speak of the necessity of understanding the trauma they experienced as in great measure socially and historically shaped in a specific manner.

The trauma my informants experience speaks to the absurd and contradictory understanding they have of their own life and death. They are

continually exposed to the experiences of other patients, presumably similar to their own. The repetition of this exposure, through both monthly routine chemotherapies, and the number of other patients they witness going through the same procedures, enables for a specific understanding of the continuous threat to one's life:

”The survivor is forced to, continually, confront it over and over. For conciseness then, the act of survival, as the experience of trauma is the continual confrontation with the necessity and impossibility of grasping the threat to one's own life. It is because the mind cannot confront the possibility of its death directly that the survival becomes for the human being, paradoxically, an endless testimony to the impossibility of living” (Caruth 1996, 25).

They are bearing witness to the deaths of others, which they identify as their own and do not speak about it. Simultaneously, their life is not really theirs to begin with, and as long as they are in the hands of the extensions of the fetishized omnipotent state of socialism they are well taken care of and their life is guaranteed. I claim that there is a dual narrative of being ill in oncology wards in Serbia. These narratives are not mutually exclusive as it might seem. They are invoked by the same people and alternate their appearance depending on the context of the conversation. Hopeful expectation of a skillful treatment provided by oncology doctors at medical institutions in Serbia that will result in full recovery coexists with the narrative of a certain death. These narratives are shaped by a dynamic relationship between emerging imageries of the capitalist future and nostalgic understanding of the socialist past.

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## Oplakivanje sutrašnjice: nada i beznade na odeljenjima za onkologiju u Srbiji

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**Sažetak:** Ovaj rad, napisan na osnovu etnografskog terenskog rada koji je realizovan tokom leta 2014 na dve onkološke klinike u Srbiji (Institutu u Kamenici i Vojno-Medicinskoj Akademiji u Beogradu) ima za cilj da napravi vidljivim procese koji se odvijaju u prostoru onkoloških klinika koji formulišu odnose između pacijenata i njihovih lekara, kao i između pacijenata međusobno. Ideje o tome koje su uloge građana a koje odgovornosti države su istorijski i geografski specifične i cilj ovog rada je da osvetli mehanizme putem kojih se nadanje i gubitak nade manifestuju u postsocijalističkom kontekstu onkološke klinike. Promišljanje sopstvenog položaja unutar komplikovanog zdravstvenog sistema u Srbiji je u velikoj meri intenzivirano samom urgentnošću za donošenjem odluka kao i neposrednim svedočenjem o umiranju i patnji. Manevrirati kroz rastući broj opcija za lečenje u polju onkologije, koji je proizvod sve većeg broja privatnih klinika, najčešće ekonomski nepristupačnih za moje informante, proizvodi anksioznost i neophodnost za reprodukcijom zajedničkog, univerzalnog narativa o tome šta znači biti pacijent onkologije. Ovaj narativ je u velikoj meri pod uticajem nostalgичnih ideja o socijalističkom i postsocijalističkom idealu odnosa države kao ktitora i građana kao subjekta kog treba zaštititi. Analiza ovih narativa ima za cilj da doprinese razumevanju načina na koje pacijenti onkologije u Srbiji zamišljaju svoju budućnost i mesto unutar komplikovanog i haotičnog procesa lečenja teške bolesti. Pacijenti dve pomenute onkološke klinike, identifikuju sebe sa svojim „cimerima“, čiji tok lečenja uglavnom znaju detaljno koliko i svoj, i formulišući svoj položaj kroz dihotomije pacijent-lekar, autoritet-subjekt i nada-odustajanje upućuju na važnost promišljanja uticaja koji prostor klinike ima na perpetuaciju narativa o socijalizmu kao i odgovornosti i ulozi lekara koji su shvaćeni kao fetišizovani produžetak državnog aparata.

**Ključne reči:** postsocijalizam, onkologija, nada, patnja, očekivanja, dužnost, država, građanin, budućnost