

THE ROLE OF DIGITAL AND ORAL MEDIATION OF POST-COVID SYNDROME EXPERIENCES: NARRATIVES OF PAIN AND SUFFERING

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Abstract: This paper analyzes the narrative reports and testimonies of people with the experience of post-COVID syndrome within the digital space (on Internet portals and social media), in everyday communication and ethnographic encounters.

In everyday communication, the post-COVID syndrome is narratively shaped into a string of symptomatological personal narratives and narratives of personal experience about symptoms and is described, both among healthcare professionals and convalescents, as an “indescribable”, “surreal”, “bizarre”, “frightening” experience, an experience of long duration, unpredictable course, unknown causes, that evades language and the hitherto familiar symptomatology and descriptions of pain, weakness or suffering. The aim of this paper is to analyze the language used for communicating the so-called post-COVID syndrome in different agoras (Foley 2012) and genres, with the goal of showing that the antagonism between language and pain opens up a wide and varied range of expressions, pushing us toward language, which in turn makes possible the communication of an experience that is in the narrative and sensory sense unfamiliar to most people.

Keywords: post-COVID, digital mediation, oral mediation, pain, suffering

[T]he one way of making people hang together is to give 'em a spell of plague. You've only got to look around you

(Camus 1991 [1948]).

Language, indeed every language, is the language of pain

(Hamacher 2017: 965).

Introduction

Since the start of the pandemic, Croatian media sporadically reported testimonies of mainly public figures who have survived the coronavirus infection¹. Their reports on the illness were the first publicly available

¹ One of the first noted extensive testimonies was the one given by the writer Slavenka Drakulić who was treated in Sweden. See on the link: <https://rb.gy/7307t> [Accessed 15.01.2023]. Other prominent figures also spoke about the course of the illness, such as scientists, politicians. The media reported social media posts of public figures (<https://rb.gy/ew9fw>; <https://rb.gy/8nhew> [Accessed 15.01.2023]). The testimonies were disseminated through interviews, television appearances and social media posts. Every experience became news. Apart from national famous people, Croatian media

accounts of the experience, while most people hadn't yet encountered it. The symptoms of the disease which was experientially unknown, often "indescribable" and "inconceivable" to the majority, gained its narrative stronghold, its paradigmatic examples and "constructed" expectations, fostered and directed fears. Over the course of time, the public became familiar with the disease's many symptoms and it became experientially recognizable, its symptoms, specific sensations, and course became more available to language. As there exists an increasing number of people who recovered from the infection, the narrative of its course is, on the one hand differentiated through many diverse experiences (from the mild, barely noticeable changes, to dramatic and fatal outcomes), and on the other universalized as an illness which has but one rule – there are no rules. This narrative makes it "frightening" but also gives one hope that their experiences will not be that "terrible".

It was not until a year after the pandemic broke those narrative reports and testimonies of the so-called post-COVID syndrome started appearing in the media and everyday communication². This syndrome is recorded in people with the history of severe illness, but also in those with mild symptoms. Media also report on research about the consequences of the illness³. It is certain that the pandemic, even once it is over, will leave behind a large number of people with impaired health, a changed perception of self, one's strength, life energy, possibilities, etc. It will also leave behind numerous experiences and personal narratives of pain, helplessness and suffering, and the struggle for the right to the story of one's experiences.

When the syndrome found its way to media outlets, even for months afterwards, it was characterized as a medical "unknown", and is still not fully acknowledged by the patients' social milieu and medical staff. In everyday communication, it is narratively shaped into a string of personal narratives, and narratives of personal experience⁴ about symptoms and is described, both

also reported about the experiences of public figures from the "West": politicians, athletes, actors, influencers, etc.: <https://rb.gy/wvq7k>; <https://shorturl.at/kwEJ5>; <https://shorturl.at/agoAS>; <https://shorturl.at/bgpEH>; <https://shorturl.at/feIW7> [Accessed 15.01.2023].

² Some of the examples of media reports on the long COVID and post-COVID syndromes: <https://shorturl.at/bjLAY>; <https://shorturl.at/owCG4>; <https://shorturl.at/dAGM3>; <https://shorturl.at/ehFO1>; <https://t.ly/FuTH9> [Accessed 15.01.2023].

³ For examples of such research see: https://t.ly/eCK_v; <https://t.ly/n9nw5> [Accessed 15.01.2023].

⁴ More on the difference between personal narratives and narratives of personal experience, whereby the former are defined by, among other things, their iterative pattern, and the latter by not being thus limited, see Marković 2010. On personal narratives see for example: Bausinger 1958; Dégh 1985; Stahl 1977a, 1977b;

among medical experts and convalescents, as an “indescribable”, “surreal”, “bizarre”, “frightening” experience, an experience of long duration, unpredictable course, unknown causes, that evades language and the hitherto familiar symptomatology and descriptions of pain, weakness or suffering using linguistically available and familiar registers.

This article looks to analyze (auto)ethnographically⁵ the language convalescents use to communicate the so-called post-COVID syndrome in different agoras (oral, print or textual and electronic) (Foley 2012) and genres. It also aims to draw attention to the wide space of expression opened up by the antagonism between language and pain, pushing us towards language that allows for communicating experiences unknown to most people in the narrative and sensory sense. The goal is to analyze how digital and social media content partake in mediating the experience of “indescribable”, “surreal”, “bizarre”, “frightening” symptoms that had initially been difficult to communicate with the patients’ surroundings and medical professionals.

Methods of analyzing post-Covid’s entry into language

The following reflections are based on ethnographic material, conversations with people having different symptoms and unpleasant sensations after the infection, persons suffering some sort of physical and psychic agony, pain and suffering. They are also based on my own experience of a six-month-long struggle with this syndrome (from December 2021 till May 2022). Apart from personal accounts of convalescents, the theoretical starting points of the paper are also based on the medical documentation of persons suffering from the post-COVID syndrome, especially on the narrative part called in the medical vocabulary – medical history or anamnesis.

In February 2022, while suffering from post-COVID syndrome, I announced my research intentions on social media and invited my private Facebook contacts to participate in the research. In this manner, I made contact with five interlocutors who connected me with another eight, all of whom I conducted interviews with. The conversations were open, we shared a common experience of pain, helplessness and suffering. Six of my interlocutors showed me their medical records. During the research, I also relied my own diary of symptoms, not kept with a research intent in mind, but as a means of easier communication with doctors and attempting to find a pattern for interpreting and comprehending my condition. I also used my own medical record in the course of the research. “Along the way”, in waiting rooms, hospital wards, emergency rooms, doctors’ offices, at work, I encountered people who narrated sequences of their experiences. I recorded

Robinson 1981; and on narratives of personal experience e.g. Labov 1972; Labov and Waletzky 1997/1967; Bauman 1986.

⁵ More on autoethnographic methods see e.g. Okely 1992.

them afterwards. I also came across many testimonies in the media and social media⁶. I was interested to observe the relation between the hitherto unfamiliar experience – the post-COVID syndrome – and language, and the role of media and social media in communicating it. I wanted to know whether and to what extent this experience can be verbally communicated in different contexts (within families, in everyday encounters with people who are familiar with the experience, but also those who aren't, in medical contexts while communicating with medical staff of different specialisations and experiences, in the media, etc.).

Other than by patients, the experience of illness (including those that at a certain period were new and unfamiliar, such as HIV/AIDS) is written and spoken about by the members of their families, by doctors, caregivers or writers. These narrative forms are grouped under the term *illness narratives*, and refer to autobiographical utterances of illness and appear in fictional forms, blogs, academic or pseudo-academic comments (Jurecic 2012: 2). In the late 20th century stories about illness and disability, helplessness, etc. have been established as a literary genre.⁷ The humanities have primarily dealt with the importance and effects of narrating illness and focused on autobiographical narrative texts centred on the patient's voice in relation to modern medicine, its stakeholders, structure and procedures, hierarchies, etc. (Brody 2003 [1987]; Charon 2006; Frank 1997; Hawkins 1999; Hunter 1991; Kleinman 2020; Mattingly 1998). A wide variety of texts, from literary and popular to medical, influenced the construction and uniformity of images related to the experience of an illness and expectations concerning it. For patients and medical experts these images in turn became the paradigmatic examples of experiencing a certain illness, its course, they related bodily experiences with language, etc.

The fact that the post-COVID syndrome was only recently recognised as a condition/illness with numerous different symptoms allows us to focus more clearly on the relation between pain (not necessarily physical) and suffering, and language, and on the processes leading to the narrative distinctiveness of the experiences of this syndrome, its validation in the everyday context, in the media and medical institutions. The new set of symptoms grouped under the name “post-COVID syndrome” still does not have its paradigmatic examples and uniform ideas and expectations and is

⁶ See for example the Facebook group “Koronavirus Hrvatska – COVID19 – savjeti i informacije“ [Coronavirus Croatia COVID19 – advice and information] counting over 40 000 members, which, as the descriptions says, is not related to “relevant authorities’ or any other government or non-government organisations”. Occasionally, it published post-COVID experiences and people could, among other things, find information about the syndrome.

⁷ On the history of illness narratives see Jurecic (2012: 4–10).

therefore theoretically intriguing. From the methodological point of view, it is also challenging to research the moment when the post-COVID syndrome enters language, since pain and suffering it causes are still “raw” and not possible to appropriately textualize and communicate, as language is not designed to verbally articulate each new “raw” piece of material of pain and suffering or to integrate it into the totality of everyday experience material without the struggle for the language itself. Herein lies the significance of the initial media reports, social media testimonies and (auto)ethnographic research. They are important because they provide insight into the entry points of the experience of pain (not necessarily physical) and suffering, in our case the post-COVID syndrome, into language.

The “indescribability” of the Post-Covid experience and its witnesses

The indescribability of the post-COVID symptomatology and the difficulty to communicate it due to the “newness” of the experience should be viewed in the context of the hypothesis of Emanuel Levinas, who holds that even when we are ready to gain insight into someone’s suffering, we are always in danger of failing to give it enough significance (1988: 156).

When you have this shit, it is terrible that, when it lasts long, a lot of people don’t have the guts to tell you they don’t believe you. They become numb. They look at you like you’re crazy. My husband used to tell me to snap out of it. “Your test results are OK, it’s all in your head”. I couldn’t move my body for weeks. I go to the bathroom, sit on the toilet, sweat, take off the stinking pyjamas, then I get cold and put something over my shoulders, I sit for a bit longer and then slowly get back to bed because I don’t have the energy to take a shower. It was like that with everything. You can’t do anything. Even you don’t believe it is possible and you see there is no way for others to understand how you feel. You see that the ones who are compassionate believe you, but have no idea how you feel. Like, OK, but how? I even felt anger from some people. They can’t look at you and then they get angry or avoid calling you or stopping by. You feel completely alone and that is perhaps the worst

(38-year-old woman).

Literary historian and theorist Elaine Scarry emphasizes that to speak of one’s own pain and the pain of another person means to speak of “two wholly distinct orders of events” (1985: 4). From the perspective of the person in pain, the pain is easily comprehensible, while for the person who is outside of the body in pain, this easiness is absent. It is easy to overlook someone’s pain and suffering, doubt its existence or force, to keep “the astonishing freedom of denying its existence” (1985: 4). In this way pain is on the one hand undeniably present and impossible to deny, and on the other impossible to confirm (1985: 4), it is something we are privileged to either accept or refuse, sympathize with or ignore. When it comes to a landscape that is

experientially unknown to most people, communicating symptoms that cause pain and suffering becomes more complex. For example, we all know what it means to “have the flu”. We are familiar with the course of illness and recovery, which is not the case with post-COVID syndrome. The fact that the syndrome implies a whole range of possible symptoms, and that few people experienced it, makes the communication of “being in pain” (Bourke 2014: 9) complex in terms of perception and communication.

Severe pain (as well as helplessness and suffering) is an intense human experience that overwhelms us and directly affects our feeling of the self. Philosopher Ilit Ferber writes that pain destroys the integrity of the self and that “instead of feeling ourselves *in* pain, we *become* our pain, united with it so that there is nothing but pain” (Ferber 2019: 4, emphasis by I. F.). Therefore, she dismisses the idea of pain as an “event” (Ferber 2019: 4). In contrast to Ferber, historian Joanna Bourke, calls pain a special “type of event” (2014: 5–9) and considers the “event” as “pain” only if thus defined by the person having this consciousness (2014: 5). She holds that through the process of naming, the person becomes or turns into a person in pain (2014: 5). For her, pain “is not an intrinsic quality of raw sensation” but a “way of perceiving an experience” (2014: 7), the “way we *evaluate* the injury or stimulus” (2014: 8, emphasis by I. F.). In short, for her, pain is “way-of-being in the world or a way of naming an event” that is never decontextualized but always relational (2014: 8). Bourke emphasizes the contextual nature of pain taking into account primarily the historical perspective, as she is interested in the positioning of pain within culture and its dominant historical conceptualizations. She defines “being in pain” as a “multifaceted sensory, cognitive, affective, motivational, and temporal phenomenon” (2014: 12–13), and pain as everything people have considered painful through history up until the present (2014: 9). Pain is an “event” that changes not only the person “being in pain” but does something to others as well.

Ferber does not think of pain as an event primarily because in pain “[t]here is nothing but pain: neither past nor future, and especially no reference point to ‘when it is not’” because “it completely fills us, condensing our identity, temporal experience, and relationship to everything outside us and outside it” (2019: 4). Therefore, life in intense pain (Ferber does not limit it only to physical pain, as I do not in this paper) “is not an event or a condition”; it pushes us into an “existential condition” in which we “*become* our pain” (2019: 4) that has its own particular organizational principle.

This pain in my legs and back... It’s like someone peeling my nerves with a razor blade. You are so helpless in this pain. You feel like you are half-conscious. You are here but not here. There is nothing you can do. There is no past, no future. It’s all the same to you. You just want it to stop. You don’t see a way it can stop, especially because the doctors have no idea how to help you. They order some pointless tests you have no energy to do. You can’t escape.

You can't go forward, you can't go back. Like being stuck in the moment, unable to change anything. And it goes on and on. And you ask yourself: 'Is this my life now, forever?'

(40-year-old woman).

This "existential state" the pain puts us in has a strong transformative potential because it does not allow us the existence we have been used to, nor the communication we more or less easily conducted. Pain transforms the witnesses as well, through its specific organizational principle. Intense pain attracts all the attention of the person in pain and of the witnesses as well, but the witness can turn away from it. The turning away is not necessarily cognitive and emotional. It is more a kind of self-protection from the overwhelming experience of another person's pain.

Fuck it, it is a very transformative experience. You are forced to question everything. You see everything in a different light. Especially the people around you. You don't see a way out, nobody helps you. Fuck, some people you hardly know get engaged in it, and at home, they treat you like a lunatic. At the hospital as well, but less so. I will never be the same after this. Never. You have to touch rock bottom to see who is around you. People are not evil. They just shit their pants when faced with something they don't understand. A triple fracture is better than this shitty syndrome. Everyone does their best to fix your fracture, and this...

(52-year-old man).

Communication with one's surroundings changes significantly. It is verbally impaired, but also very intense. With the post-COVID syndrome, the communication between healthcare professionals and the person that suffers is impaired, primarily due to the lack of exactness that medicine usually relies on in diagnostics. Namely, the post-COVID syndrome is very strong on the sensory level. The different sensations, when viewed jointly, do not correspond to the algorithms of the medical profession or the techniques of scanning, analyses of bodily fluids and tissues, and other diagnostic procedures do not confirm the usual, known diagnoses and hinder the following of usual medical protocols.

The medical documentation of my informants in the part that is in a medical language called anamnesis, contains short descriptions of symptoms that healthcare professionals extracted from the patients' narratives of personal experience. Some of the descriptions marginally resemble conventional medical histories, emphasizing the "bizarre" quality of the symptoms; gathered in one place they demonstrate diversity. Some of them are, for example: "the feeling of weakness", "shivers", "weakness in the legs", "as if the hands weren't her own", "feeling as if her thumbs are not listening", "mess in her head", "the feeling of cold in the body but without high

temperature”, “constant mild nausea”, “weakness in the jaw”, “occasional vertigo”, “blunt pain below the ribs on the left side, without breathing difficulties”, “states that mental effort is required to move hands”, “can sleep only in foetal position on an armchair”, “cold limbs during the day”, “background smell of ‘roasted mucus’”, “cacosmia (of gas and burnt food)”, “legs start trembling soon after she starts walking”, “unrest in arms and legs”, “feels like she will explode”, “strong joint pain”, “states previously unknown agitation”, “insomnia, wakes up every 15 to 20 minutes”, “feels like she has no muscles or bones and that it is all an undefined mass”, “agitation”, “night sweats, frequently awaking, intense dreams”, “feeling as though digestion is at a halt”, “doesn’t feel hunger until she tastes food”, “no feeling of fullness despite eating a larger amount of food”, “feeling as though the food is rotting in the stomach”, “sour and mildly metal taste in the mouth”, “after having eaten, symptoms of unrest become more pronounced”, “forgetfulness”, “disruption of menstrual cycle”, “states that he feels as if someone covered him in poisoned gas”, “balloon in the head”, “breathlessness”, etc.

During interviews, the convalescents offered descriptions of symptomatology as parts of larger narrative units with detailed description of the experience, narrative positioning of the symptoms within the wider context of one’s life, narrative formation of concern, fear and anxiety. The informants often emphasized the “indescribability” and newness of the experience. Their narratives of personal experience and personal narratives, reformulated or translated in medical institutions into the genre of medical history, include the feeling of powerlessness to communicate the symptoms when asking for medical help.

At some point, I started questioning my perception, the symptoms... After several visits to the emergency room and relatively good test results, the ER head asked me whether she should call a psychiatrist. I thought to myself, call whomever you want. Then a young doctor came and concluded I was “normal”, but fuck me, who knows. If the results are OK, and I feel horrible both physically and mentally, maybe there is something wrong with me. I had never felt like that in my life, or, more precisely, I had never felt all those symptoms all at once. It is like you are falling apart in all areas, and nobody knows what’s wrong with you, and they give it a name, a syndrome. Slowly you start to realize that you can’t get any help, that there are no words to describe the level of suffering. I withdrew into myself then and accepted that I would probably die. It’s not possible to feel that and live for long. I tried to tame the overwhelming fear and it was totally acceptable for me that I should die at some point. I got tired of fear and suffering. I just wanted it to stop. I was terrified by the idea that that would be my life

(48-year-old woman).

The previous example shows how complex communicating the post-COVID syndrome is, not only in everyday communication with witnesses, but also in

the context of healthcare. In the latter case, we can discern two different communication registers and genres the stakeholders use to “understand” each other. On the one hand, the patients narrate and communicate their corporeal experience by struggling for a language comprehensible to others, and on the other hand stand the specific medical procedures doctors use to translate the patients’ statements into medical records, confirm their diagnosis using preset, specific procedures and suggest a treatment plan. Difficulties in communication occur due to the fact that the post-COVID syndrome, as initially a new and unknown group of symptoms, was not “measurable” in the same way other, known diseases and conditions are, and so the patients have often been directed to psychiatrists (as a “softer” profession), who were supposed to explain the disparity between the patient’s “indescribable” story and/or described bodily experience and the failure of precisely organized diagnostics. Pain being on the one hand a doubtless fact for the person in pain and on the other something questionable, increases the suffering of the person already in pain and puts her/him in isolation from the world in terms of communication and therefore also in physical terms, the world that up until then seemed familiar and domesticated.

Describing the “indescribable” and the struggle for language in pain

The previously mentioned media reports and social media groups have been of great help to the convalescents as they provided cognitive and emotional foundations for their experiences that had been unknown to the majority of people. For example, I read an unusual description of the post-COVID syndrome in the media that resonated with my own experience and the experience of some of my interlocutors. In this report, the syndrome was described as “fatigue on ecstasy”⁸. After I had mentioned this description, one of my interlocutors described this “symptom” in the following way:

Excellent description! It’s exactly that! Now, you tell me, how can anyone understand that? There is no escape. You have to move and you can’t stand on your feet. You can’t even lie down. There’s no describing it. It is totally impossible to describe it to anyone. Imagine describing it to a doctor: “I feel like I’m tired on ecstasy” you go straight to the madhouse. If you don’t see it in the blood or on x-rays, straight to the madhouse. I felt helpless and I am not entirely sure it is behind me

(50-year-old man).

Despite many post-COVID clinics having been opened, the convalescents I spoke to have not been able to receive some type of a consult or comprehensive care as they were set up as part of clinics for pulmonology

⁸ “Dugi Covid”/“Long Covid”, <https://shorturl.at/doqvH> [Accessed 15.01.2023].

or neurology. My interlocutors were forced to research and describe the “indescribability” of their experiences on their own; they became members of different social media groups, trying to find a connection between their own symptoms and the conditions and diagnoses known to medicine. They were forced to communicate the “indescribable” and the “inconceivable”.

Three months had gone by until I realized my problem was gastroenterological. I wouldn't have recognized it if I hadn't searched the internet. I had no pain but I was weak and couldn't eat. For days. I was completely exhausted. I couldn't walk or eat. I lay motionless. At some point I would eat something and then feel overwhelming anxiety like I had been poisoned, and I get a rash. I am dying. At first, I didn't connect it with food. I literally thought I had gone crazy, but I read the experiences of others... Everything stayed inside me and rotted. If I was hungry, I was weak; if I ate anything, I was crazy. I visited a couple of gastroenterologists. One said, have an effervescent multivitamin tablet. Genius. Another said I might be allergic to histamine. I do the test – not it. Then I visited one who understood everything, he made notes, looked at me as a kid being told a super interesting story. He got it all. He said he understood, I was not the only one. He had heard dozens of similar stories. I had also read all kinds of stuff... Whomever I mention it to, they look at me like I was crazy. I started feeling hopeful that I might get out of that. There is a solution. I talk for half an hour. After everything, he told me my microbiota or whatever was disrupted but... “There is no help. Usually, it goes away in three to six months. A year.” A year? On the one hand, great, I'm not crazy, there are more like me, but on the other, no way I can survive a year like this. I could barely climb up the stairs. Skinny, weak. Horrible...”

(my testimony during an interview).

These examples show several things that are important for further discussion. In the conditions of physical isolation that was initially mandatory and later advisable, digital media (mostly news portals) reported on the experience of the post-COVID syndrome. They published social media posts of public figures and sensationalist descriptions of public figures and “regular” people who had had the experience of the post-COVID syndrome. These reports followed the lucrative sensationalist logic, as the experience of the post-COVID syndrome proved fruitful as “indescribable”, “bizarre”, “frightening”, etc. This logic aside, in these reports the convalescents found consolation and indirect support for explaining to themselves and the witnesses (people close to them and healthcare professionals) their experiences and validating them. Although unintentionally, these reports had the function of the struggle for the language in pain as they made the pain publicly available for others to understand and for witnesses to respond to emphatically, but they also incited fear and concerns. People who shared these experiences gathered in social networks, exchanging the stories of their

symptoms and personal experiences of the syndrome, trying to find a way to “squeeze” their pain into language and find help.

The convalescents’ notion of the post-COVID syndrome experience as “indescribable”, which is built into numerous narratives about the condition, opens for me the crucial issue I want to address in this paper: do pain and suffering suppress language, destroy and annihilate it, isolate us from others who lack the experience or is the case rather that the yet unknown syndrome opens a wide and varied range of expressions, pushing us towards language exactly because of the antagonism between language on the one hand and pain and suffering on the other?

Writings in the humanities that deal with the relationship between pain and language form, roughly said, two dominant paradigms. The first one emphasizes the destructive nature of pain, where pain incapacitates the body, thus destroying our linguistic and narrative capacities and the ability to communicate. The second paradigm emphasizes the isolating effect of pain. According to this strain, pain creates a rift between the subject experiencing pain and others. Ferber notices that “[a]ccording to the first paradigm, pain is fundamentally characterized by its *destructiveness*; according to the second, pain is violently *isolating*, turning us into enclosed, solipsistic entities. Pain dismantles our world and being and our ability to actively exercise our subjectivity, not only because it literally destroys our bodily integrity, but more important, as a consequence of its impact on our linguistic, communicative capabilities, it renders them virtually powerless” (Ferber 2019: 8). These two characteristics of pain, its destructiveness and isolation, are evident in most of the examples listed here, both in the communication with the patients’ families and the healthcare professionals. Hence, the center of the first paradigm is the destructive nature of pain and suffering, it emphasizes the violence pain inflicts on the body, psyche and the sense of self and the second relates to the unique way pain isolates us from others, creating a rift between those in pain and those witnessing pain. The second paradigm stresses that pain does not only disintegrate the body, but also our ability to relate and communicate to others (Ferber 2019: 145). Pain and suffering, therefore, prevent us from communicating and sharing. Separating us from our own selves, it separates us from others as well.

However, in her book *Language Pangs* (2019) Ferber shows that these two paradigms not only consider the experiences of pain (the destruction and isolation it brings) but also the importance of the relationship between pain and language. Pain is an experience that is very strongly connected to language and expression, although it challenges language and communication, “making it always and essentially an experience of language: first, by virtue of the collapse of articulate language in the face of pain; second, through the strong connection between the experience of pain and the urge to express it, on the one hand, and the consummate impossibility of

saying anything about pain, describing it, or communicating it, on the other” (2019: 145).

This is the key to the interpretation of the post-COVID experience as well as the postulate of the third paradigm that becomes visible in the collected narratives. As a new disease, a syndrome or a set of symptoms, this experience attempts to “push into” language (due to the need to communicate the bodily experience or to search for help in medical institutions). In other words, pain and suffering brought about by the so-called post-COVID syndrome require expression while simultaneously precluding its articulation, although not necessarily in an antagonistic manner, by way of confrontation that is comprehensive and destructive. Ferber notices that the fierce antagonism between pain and language put forth by the first two paradigms “reveals that pain is most accurately defined in relation to language, and language makes itself manifest in relation to the experience of pain. In other words, it is exactly because their point of departure is in violent opposition that the association between language and pain is undisputable” (2019: 145–146).

As much as pain and suffering in general, and more specifically in the context of the new set of symptoms we call the post-COVID syndrome, are difficult to communicate and isolating, it is never the case that the trouble with language in pain ends in this antagonism, regardless of the problems in communication between the person in pain and for example healthcare professionals. It would appear that at the point of the painful inability to communicate pain and suffering, at the point of violence pain inflicts over the body and communication, the point of the lack of understanding between the person in pain and other, is the very point where communication begins. Therefore, it is not necessarily about the narrations originating from the ruins of language, its fragments and splints. It is the dissonance and antagonism between language and pain that ensures the power of language and the ability to express. Also, the isolation from others that pain causes is not the only effect of pain. Regardless of the undermined ability to communicate, pain and suffering also “push” us toward the Other, even when this does not produce clear empathy and a meaningful ethical response. Pain deepens our relationships with others and opens a wide and varied range of forms of expression.

Although we are very intuitive in accepting that pain is destructive and isolating and build this experience into our narrative of pain, the space filled by each individual representation of pain as destructive and/or isolating remains vague as it “necessarily implies a strong and incontestable linguistic presence” (Ferber 2019: 12). For instance, the utterances of my interlocutors – “Horrible!”, “Indescribable”, “There are no words to describe this horror” – remind us that language contains space for these experiences, albeit limited. The person in pain struggles to conquer this space, in an attempt to find a

suitable way to occupy as much as possible of the linguistic, narrative and symbolic space for her/his experience of pain and suffering, in spite of the difficulties brought about by the destructiveness and isolation of pain. The experiences of my interlocutors, as well as media reports and social media posts demonstrate this: it is in the antagonism of language and pain that communication finds its most intense beginning, persistent to occur, to bring us closer to another person, to ensure our existence, procure help. At the same time, we are aware that none of the positive outcomes is inevitable, that we can remain misunderstood, alone, isolated in pain and suffering. This uncertainty renders the person in pain even more vulnerable, the pain more unbearable. But in pain we have no choice but to remain, endure, push through.

Convalescents' testimonies clearly show that people around them initially didn't trust or more or less doubted their story, but in the end those who talked about their symptoms, despite the lack of understanding on the part of their surroundings and the medical profession, contributed to the fact that the experience that was experientially and medically "unusual", "bizarre", and "inexplicable" is at least treated as valid, although Western medicine barely has diagnostic guidelines and treatment methods for the syndrome. What lies in the background of the struggle for language in pain is also the fact that our public health system is not focused on anything that makes us human apart from the bodily functions and medically relevant parameters and procedures. The new syndrome following the infection reveals this collision in an even clearer light, but this is another topic.

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УЛОГАТА НА ДИГИТАЛНОТО И НА УСНОТО ПРЕНЕСУВАЊЕ НА ИСКУСТВОТО СО ПОСТКОВИДНИОТ СИНДРОМ: НАРАТИВИ НА БОЛКА И НА СТРАДАЊЕ

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Резиме

Во трудот се разгледува почетокот на навлегувањето на медиумското и на усното, наративното посредувано искуство на постковидниот синдром во јазикот, во форма на серија симптоматолошки лични наративи и наративи на личното искуство. Врз основа на извештаите, посредувани од медиумите и од (авто)етнографска перспектива, јазикот што го користат реконвалесцентите, за да го опишат т.н. постковиден синдром на различни начини и во различни жанрови, има цел да укаже на тоа дека антагонизмот на јазикот и болката отвора широк и разновиден опсег на истражувања, туркајќи нè кон јазикот, кој овозможува комуникација на наративно и на сетилно непознато искуство, без

оглед на тоа што болката и страдањето го потиснуваат јазикот и тие ја отежнуваат комуникацијата и нè изолираат од другите. Иако, болката и страдањето на соговорникот, ги доведуваат во прашање јазикот и комуникацијата, тие, сепак, се поврзани многу силно со јазикот во антагонистичката борба меѓу колапсот на артикулираниот јазик, од една страна, и силната потреба за изразување на болката и на страдањето, за комуникација со околината во потрага по разбирање и сочувство со сведоците, и медицинската помош, од друга страна. Трудот, врз основа на бројни примери на сведочења од реконвалесценти, покажува дека иако, болката и страдањето, се соопштуваат тешко и иако тие водат до изолација, сепак, тие не водат до антагонизам меѓу јазикот, кој искажува болка, и јазикот генерално, и покрај сите проблеми во комуникацијата меѓу лицето што страда и сведокот.