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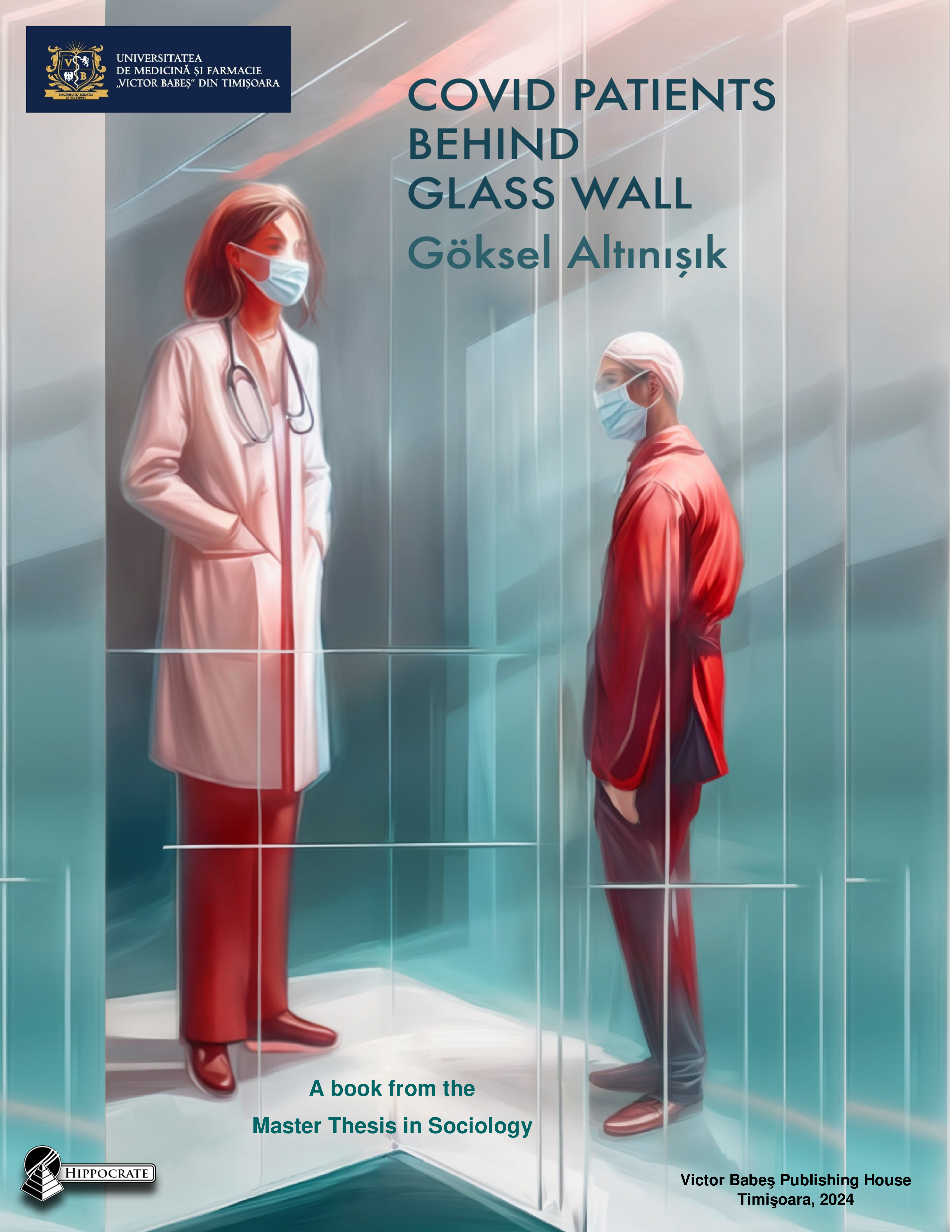

COVID PATIENTS BEHIND GLASS WALL

Göksel Altınışık

A book from the
Master Thesis in Sociology

HIPPOCRATE

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To Nuriye and Mustafa Altınışık,

the reasons of my existence

İÇERDE

Pencere, en iyisi pencere;

Geçen kuşları görürsün hiç olmazsa;

Dört duvarı göreceğine

INSIDE

A window, the best is a window.

You’d better see birds flying, at least,

Instead of seeing just four walls.

Orhan Veli

Acknowledgement

I realized that bearing witness to the extraordinary period we were experiencing was invaluable, and I encouraged everyone around me to document their own reflections on the pandemic. Writing has always been as essential to me as breathing, and during the pandemic, it became even more vital; I found immense joy in creating and the real fortune of doing so with people who shared this journey.

I am grateful to my esteemed professor, the head of the sociology department where I completed my master's degree, İsmail Coşkun, for giving me the opportunity to study in this field. I would also like to thank my advisor, Enes Kabakcı, for his kind and supportive guidance throughout my master's thesis in Sociology. Without his help, this work could not have been written or shared to bring insights from the patients' perspectives. My deepest gratitude goes to my husband and fellow writer, Ali Ergur, who supported me in every way; to Gizem Kosova, Şadiye Nuhoğlu, Ramin Alizadeh Gheshlagh, Nazlı Çetin Beyaz, Jeanne Dubino, Gabriela-Mariana Luca, Craig Coss, and Hakan Altınışık, who encouraged me to publish this book in English and assisted with proofreading; to my colleagues from both of my professions, who inspired me to keep moving forward; to my parents, Nuriye and Mustafa Altınışık, who once again shared the stresses of my writing journey; and to my daughter Özge Kıter, who designed the cover of book and constantly reminds me how proud she was of me.

Those devoted to writing know that one of the most challenging stages is publishing it as a book. At this critical point, my esteemed publisher Barış Kapukıran opened the doors of Raskolnikov Kitap to me, as always. I am deeply appreciative of this opportunity and thank him from the bottom of my heart. Publishing part of this book in English became possible because of this first step. Later, Victor Babeş Publishing House received this e-book with open arms, as they did for *As Our Hearts Keep Beating*. Their team not only gave me the chance to publish books but also provided easy and quick access to international readers.

This book is a source of awareness and remembrance thanks to the collaboration of patients who shared their experiences with sincere generosity. Without their contributions, this would have been solely a theoretical discussion. I am thankful for their collaboration, which has left a mark on history through my research and writing. The lessons I gained from this study have deeply shaped my medical practice and my passion for medical education. Now, it is time to share these insights with the world.

CONTENTS

The doctor was still looking out of the window.
Beyond it lay the tranquil radiance of a cool spring sky;
inside the room, a word was echoing still, the word "plague."
—Albert Camus, The Plague

Preface

When I started my undergraduate studies in Sociology as a second university program while being a Chest Diseases specialist and a scholar at a medical school, I did not think this path would lead to where I am now. My expectation from this education was to combine my experience in the medical field with the knowledge I would gain about human sciences, in addition to conducting interdisciplinary scientific research. When I applied to the master's program in the Department of Sociology at the Institute of Social Sciences at Istanbul University, the head of the department guided me towards the field of health sociology, opening the first door. The academicians in this department sincerely welcomed and supported me, and I felt that I had become a member of a new family. When it became difficult to commute to classes because of the long-distance travel required to attend them in person, one gift appeared among the many restrictions of the pandemic: remote classes. While working in the COVID Clinic at that time, remote education sessions were like an oasis in the desert; they gave me the strength to cool down and keep going amidst the chaos of the pandemic. Looking back at the conditions under which I attended every class and wrote my assignments without missing any, I once again believe in the healing power of producing, especially through thinking and writing.

The idea to enrich the spectrum of the study population for my master's degree thesis by reaching out to COVID patients from different cities and healthcare institutions could be actualized with the unconditional help of my esteemed colleagues in reaching their patients who agreed to be interviewed. Thus, I could reach out to COVID patients, only a few of whom I had treated, and the invaluable experiences that they sincerely shared with me. I can confidently say that these interviews helped me to adopt my medical practice by highlighting the holistic perspective. Although I always prioritized dealing with my patients as bio-socio-psychological beings, this approach became more satisfying with the uniqueness of the experience. Hearing firsthand from patients and their relatives about what they felt in isolation and the wide scope of the social and psychological problems they experienced, and being able to provide a safe environment for them when narrating their story to a physician, made a unique contribution to my expectation of a mutual enrichment of the two fields. The references to walls and windows mentioned in my interviewees' statements deeply affected me. Bringing to light what they experienced behind those walls—whose purpose was to isolate them from society—could only be possible by making the walls of the rooms that they were confined in more transparent. I am glad that could achieve this mission by sharing their stories in writing.

This research became a tool for me to document the experiences of those who made history with what they lived through. The contribution I aimed to make to the future of society and my profession through my two deeply cherished fields of science (medicine and sociology) became possible by meeting readers through a book published in Turkish. The metaphor of the *Glass Wall* serves to make visible what COVID-19 patients experienced behind the walls of hospital rooms or intensive care units, and it also captures what they felt while sometimes watching the outside world from their windows. I believe that the more I can share the multi-dimensional challenges they faced and the support that made their resilience easier, the fewer social problems future pandemics will cause. Recently, I am invited to teach medicine internationally through my patients' stories with the book *As Our Hearts Keep Beating*. Soon after, I decided to translate parts of my master's thesis on the social effects of COVID-19, *COVID-19 Patients Behind Glass Walls*, to mention further the holistic approach in medicine. I am convinced that COVID-19 is an ideal model for discussing the social aspects of a diagnosis made through biological workups.

Seeing, hearing, and knowing impose a responsibility. I narrate with that feeling. See, hear, and know, so that their experiences are not in vain.

Now and always, my wish for everyone, including myself, is to "stay healthy".

Introduction

The date COVID-19 was epidemiologically declared as a pandemic by the World Health Organization (1) and the announcement of the first patient in Turkey (2) coincided. In the three preceding months, scientists primarily from China published their experiences in academic articles with record-breaking speed and volume in the history of science (3-5). Thus, reflex-like practices have been implemented to take this pandemic under control. Despite possessing a vast amount of knowledge incomparable to that during pandemics centuries ago and rapidly adapting information obtained from recent outbreaks, uncertainties persisted by the end of the first year of the pandemic. As a result, from a medical perspective, COVID-19 continued to be a global health issue. Initially, efforts focused on preventing patient fatalities, but they soon shifted to addressing the sociological, economic, psychological, and even political aspects of the situation. In addition to medical impacts, this disease has numerous sociological effects on healthcare workers combating it, those experiencing the illness, and the rest of society.

It is suggested that the reason for the increase in fear among the public due to the COVID-19 pandemic is the presence of numerous uncertainties about the new type of Coronavirus. Among these uncertainties are the contagiousness of the virus, the prevalence of asymptomatic cases, the role of environmental contact in transmission, and the highly variable course of the disease. *Coronaphobia* emerged during the pandemic. This concept was defined by Asmundson and Taylor as worried healthy people who are hypochondriacs rush to hospitals thinking they have this disease (6). The medico-social relationality here can be exemplified through such social impacts as psychological stress induced by rational choices in giving healthcare. It is a real medical phenomenon which creates a psychological burden on individuals via social means and sometimes misinformation. COVID-19 falls under the purview of not only medicine, from a biological perspective, but also sociology with its social impacts, and psychology with the emotional burden on people in many aspects. The events that transpired because of the pandemic have also taught us that misinformation spread through communication channels can increase the frequency of stigmatization and unwanted behaviors such as physical or psychological violence (7). While educating the public on the misinformation issue was declared among the proposed solutions, it was seen as crucial to focus on the phenomenon known as an *infodemic*, which refers to the rapid and widespread dissemination of both accurate and inaccurate information, which sometimes spread faster and further than the virus itself.

This quickly-spreading pandemic has transformed practices in both visible and covert ways, as occurs in any social institution. Moreover, these changing practices were likely to turn into norms rather than being understood as compulsory and temporary. According to health practices, both the visible and the covert aspects of this impact were relevant. The visible aspects increased as the pandemic attracted more attention to itself. The covert aspects increased when health institutions were, by their structure and nature, closed off (based on patient-doctor confidentiality) and became mysterious to outsiders, which aroused public curiosity. So with all these aspects, COVID-19 became an essential topic of research for many fields, including health sociology.

Considering the breadth of the research scope, a single theoretical basis would be insufficient to explain the sociological multidimensional impacts caused by the disease. The discussions in each section are based on theoretical approaches specific to the topic. Specifically, the focus is on the micro dimensions of society, daily lives, the contemporary everyday world people live in, how individuals are influenced through *symbolic communication*, how they create order and meaning, and the fundamental factors that motivate people in relation to a particular situation. In this way, it is anticipated that the disintegration and reassembly of society as a reaction to an extraordinary situation, and the possibility of envisioning society amid uncertainty, can be understood by starting from individuals' experiences of losing and regaining their bearings.

This research aimed to investigate the conditions under which COVID-19 patients were mandatorily hospitalized, their experiences of stigmatization/exclusion, and contexts of privacy in relation to widespread nature and unprecedented occurrence of the COVID-19 pandemic. To assess the social experiences of COVID-19 patients during their diagnosis, treatment, and discharge periods, the study was designed using a qualitative research method based on patient interviews. The two principal purposes of the questions included in the interviews were::

1. To address the health-related aspects of COVID-19 from a sociological perspective: The characteristics and individual-social impacts of isolation conditions, including complete disconnection from external environments (including visitors) during the treatment process in single-person isolation settings, followed by home quarantine.

2. To reveal the connections with COVID-19 in the context of interaction through: (a) An examination of labeling/stigmatization and privacy issues, focusing on the approaches reflected to the patients' relatives during the diagnosis period and the patients' own experiences after discharge. (b) An exploration of exclusion and self-exclusion experiences.

Study Design

This study has been carried out by a pulmonologist-sociologist, who set up the COVID clinic of a university hospital and worked as a clinician in the first three months of the pandemic, diagnosing and treating COVID-19 patients. The originality of the study lies in being designed and investigated by a researcher who used the experience of both fields as a physician who worked with COVID-19 patients and a sociologist familiar with sociologic methodology. In this qualitative, semi-structured case study, where online in-depth interview techniques were used, the characteristics of the isolation in a room for patients diagnosed with COVID-19 during treatment at the hospital and home isolation conditions after hospital discharge, and their individual-social impacts were determined as the main research question.

In the interview form, apart from demographic information, there were also questions about the isolation conditions during the hospital stay, the behavior of hospital staff, the contexts related to what were experienced under strict isolation questioned. The experiences of stigmatization and exclusion were investigated. The avoidance was considered exclusion; and if the interviewee stated that any stigma adjective was used during this exclusion, it was considered stigmatization. The experiences related with respect for their privacy and violation of privacy were investigated in multidimensional manner.

This study has been approved by the Ethics Board of Research in Social Sciences and Humanities at Istanbul University (Date and Issue: 07/23/2020-83423). Maximum variety and snowball sampling were used to determine the sample of the study, and code saturation was taken as the measure for ending the interviews. Interviewees were in-patients diagnosed with COVID-19 (regardless of microbiological evidence), treated in COVID clinics. The researcher asked colleagues to invite at least one patient to participate in the study to include patients from different cities around the country and eliminate the differences in clinical practices and cultural impacts in interviewing the patients of only one center. The distribution of patients according to cities is shown in Figure 1. The number of interviewees was higher in Denizli than in other cities because researcher was working in this city. The study was not just confined to the researcher's institution even in this city. Various hospitals both public and private were included as well as patients under family physicians' care. So, patients were represented at a wide range of healthcare facilities as well as socio-economic levels.

This study started four months after the declaration of the pandemic and included a total of 51 interviewees. All the interviews were completed quickly so that all the experiences spanned the same period between 13 July and 28 August 2020. This period was determined to address patients monitored across the country with similar protocols during the first three months of the pandemic. This way, different practices did not influence the experience of the patients. As we know, in following periods of the pandemic, only patients in critical condition started to be hospitalized instead of every patient. Most COVID-19 patients received treatment at home later.

The average age of the 51 interviewees was 43, between 20-67 years. They were all diagnosed with COVID-19, got treatment at a hospital, and were interviewed soon after the quarantine period. The gender distribution was 33 males (65%), and 18 females (35%). The occupational distribution was quite wide with students, housewives, farmers, factory workers, teachers, office employees, and factory owners.

In the interviews, the voices of interviewees were recorded with the informed consent of patients. With the anonymous transcription of the recordings, the expressions in the interviews were classified according to the thematic content. For this classification, the interviews were individually sorted according to thematic cohesion; and coding was done for each section to meet the abstract concepts. Those codes/labels found to be frequently used were analyzed in the main groups they belong to. The analyses were made without the help of a computer program since the total number of interviews was small enough to analyze by researcher herself.

The data analysis sections of the study were dealt with theoretically, with quotations from the representative interviews where relevant.

The originality of this research is holding a mirror to the individual experiences to record the reflections in the way chosen to express.

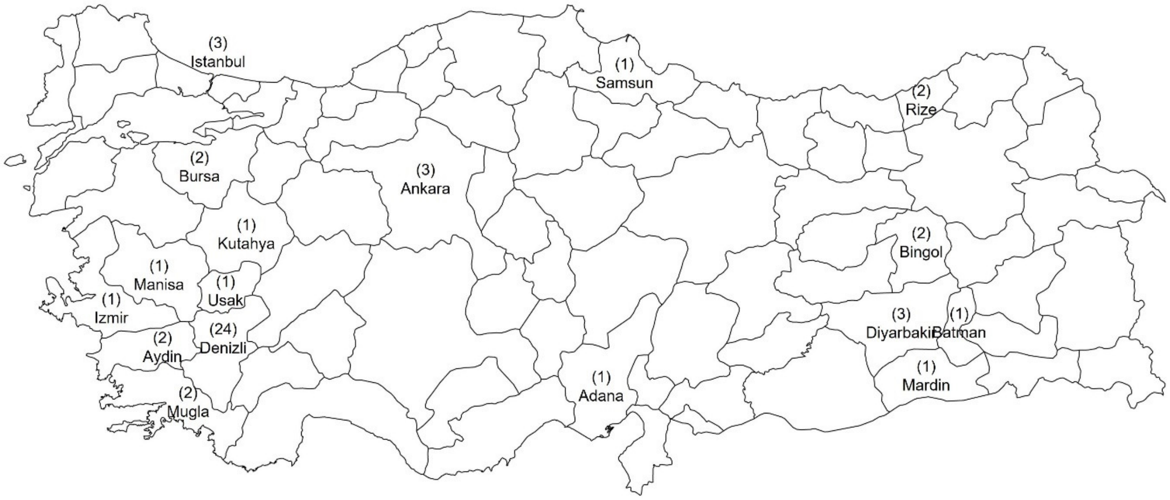

Figure 1. The map of Turkey that shows the distribution of the patients interviewed

Keywords: COVID-19, isolation, confinement, quarantine, stigmatization, exclusion, privacy, health and disease sociology, medical sociology

PART I.

Social Effects in relation to Isolation on COVID-19 Patients Treated in the Hospitals

In the first three months of the pandemic, almost every patient diagnosed with COVID-19 was hospitalized in strict isolation; and after discharge period, they were separated from society with home quarantine, commonly for two weeks. Also, with the observations of the researcher working as a pulmonary disease specialist, it has become necessary to assess periods of hospitalization and discharge in COVID-19 patients from a sociological perspective, especially in terms of isolation.

Protective measures are beneficial, even obligatory to treat patients under isolation in hospitals with high-risk infectious diseases. However, it should also be considered that patients may be adversely affected in terms of social relations. Foucault's statement in *Discipline and Punish* because of this restraint, a whole army of technicians took over from the executioner the immediate anatomy of pain: warders, doctors, chaplains, psychiatrists, psychologists, educationalists (8); encounters a lot of objections from doctors who behave ethically and professionally and who got tested in many fields. Still, it would be better to be objectively critical of this issue. Since the act has a rationale as *public interest*, such a perspective is necessary so that it does not turn into punishment when setting the refined points of the method. Implementing isolation by knowing its conditions and effects might eliminate the risk of isolation turning into an economy of suspended rights. For these practices, it was necessary to search the psychological and social impacts and learn their scope during isolation.

One of the representatives of the Structural-Functionalist approach, Parsons, posits with the concept of the "sick role," that although the individual is not responsible for their illness, they have a definite obligation to recover by following the treatment recommendations of physicians (9). An example of the internalization of this role in society is the anxiety individuals experienced during the COVID-19 pandemic about acquiring information on the disease and taking the recommended preventive measures — even measures they believed would be protective, despite not being recommended. The difficulty in accepting a diagnosis after falling ill, despite these extensive precautions, can be seen as a reaction influenced by the social norm of being healthy. Parsons links the increased seriousness of illness for the social system to its function not merely as an external threat to be avoided but as an integral part of social balance (9). In this context, individuals strived to avoid illness to the utmost extent and, when they did fall ill, fully submitted to medical guidance to recover, thus experiencing social influences during the pandemic.

Even though COVID-19 is a medical issue as a pandemic, it created a new perspective as it turned into an anomie with uncertainties and unknowns. COVID-19 patients had to be hospitalized, isolated, and quarantined; violations of privacy were normalized; interpersonal relations were transformed with changing life practices; other social factors such as economic impacts emerged due to new working conditions. For this part of the research (social effects of isolation), mainly *structionalism* and *structural functionalism* form the basis for discussing isolation concept through confinement and social system.

Findings

The codes related to experiences during isolation in the hospital specific to COVID-19 patients were presented in three groups.

Isolation is defined as keeping a sick person separated from healthy people to protect them. Quarantine, on the other hand, is defined as separating and restricting the movements of a person who is not sick yet but has been in risky contact with a sick person to keep him or her under close observation (10). World Health Organization (WHO) focused on the trio of protective measures, i.e., “mask-distance-hygiene” from the onset of the pandemic as COVID-19 is airborne and infects people via contact of hands and faces with surfaces (11). The isolation room conditions in hospitals around the country have been announced by the Turkish Ministry of Health (12). As Fan et al. stated, a decrease in the number of visits by doctors and nurses into patient rooms was recommended to minimize the risk of contamination, and thus prevent waste of personal protection gear; however, the infrequent and shorter visits adversely affected the patients in isolation (13). Similar experiences of many interviewees were observed when dealing under different sections.

1. Isolation Conditions

Isolation practices started in the emergency wards of hospitals because the onsite triage practice in hospitals were set up near the emergency wards, and regardless of their specialization, doctors were doing triage (sorting out, first medical evaluation) and obtaining microbiological samples there. Questions in the first application in the form of an algorithm or flow chart have been directed at all patients applying to the emergency service. Procedures to be used were based on their replies, and on the flexible work schedules of doctors on a rotation basis. All patients suspected to have COVID-19 were usually isolated in emergency services all by themselves; family members were not allowed to even visit them. The patients with COVID-19 diagnosis were isolated by themselves in COVID wards. The transfers in the hospitals were also made with insulated stretchers or chairs to prevent contamination. Both the transportation of patients with suspected or definite COVID-19 who needed to be admitted to the intensive care unit within the hospital and the intensive care hospitalizations have been arranged under isolation conditions. In many hospitals, outpatient clinics were either closed or continued to operate at low capacity. Inpatients were transferred to inpatient services, which were generally reserved for COVID-19 patients, and access to that department was restricted except for those on duty and inpatients. The hospitalization of the patients with their children was generally made to the wards where pediatric patients were present.

The words isolation and quarantine are used interchangeably, especially in everyday language. It has been noticed that in the statements of the interviewees, isolation of the patients in the hospital was meant by both. For this reason, it was reasonable to consider the room in the emergency service where the patient's test result was waited for while the diagnosis was not yet finalized, as a 'quarantine room'. It was observed that this waiting period, generally accompanied by uncertainty and anxiety, had a negative effect on patients. In the meantime, patients insisted that their family members stay in the room for support, but sometimes some family members hesitated because of worrying the patients even further.

Hospitalization was in the form of isolation in places that were difficult to access under all circumstances, and where patients remained alone once they entered the room so that they could not see what was happening around them. Being isolated in this room may lead to loneliness and boredom, and disconnectedness from the rest of the world (13). On the other hand, some did not feel uncomfortable; and they even think that being alone in this way has advantages, especially for protecting privacy (14). In the recent study, it was often expressed that being confined to a room by oneself, being isolated from the outside world created discomfort and burden due to thinking of relatives who could not be with them. While staying in places where access was restricted and difficult affected patients negatively, it was considered as a chance to go to these services for hospitalization without experiencing the anxiety of waiting in the emergency room. All the above were among the experiences of the interviewees.

> *There is a small room in the emergency ward called isolation. I was there for eight hours. I am a person with a phobia of indoor spaces. It was like a tiny prison.* **Interviewee 21**
>
> *On the COVID floor, reserved as the infection section, only password access was allowed, and they took us there*. **Interviewee 14**

It can be easily predicted that the isolation conditions will have negative psychological and social impacts. Since physical facilities cannot reach a certain standard in every health institution, the frequency, type, and severity of these effects may vary. While there is a difference between private and public hospitals in terms of patient room comfort, the distinction between private and public university hospitals is observed more clearly in some places. Apart from that, it can be predicted that sleeping in the service room or intensive care unit will make a great difference in terms of the physical characteristics of the space.

Among the situations that increase the negative effects of insulation on people, there is also the failure to meet the basic requirements. In some studies, it has stated that food and water distribution was intermittent and that the meals arrived late (15). Food and water are at the first level in Maslow's hierarchy of needs; right after followed by the next level of shelter and security (16). In this context, the interviewees stated their impressions related to the physical conditions of the hospital room during the isolation, especially whether the toilet and bathroom were private, inside the room, or for common use outside the room. Unless these basic requirements are met, it is not possible to move to the higher levels; and isolation conditions, especially loneliness and difficulty of focusing, can be important obstacles in this aspect.

Healthcare professionals who benefited from healthcare services as patients could gain privileges by using their social and symbolic capital by stating their professional identity when they went to other hospitals, related to their frequent presence in their own work environment. According to

Bourdieu's definition, these capitals, just as in the concrete sense, have features that are accumulated over time, serve individual benefits when used, and manage functions that bring success in practice (17). It is observed that sometimes the interviewees felt the need to state that they did not receive any privileges despite their capital.

> *I'm lucky, my sister-in-law is a doctor; we contacted home through her. Of course, news from me was also sent there.* **Interviewee 47**

> *There was no privilege concerning the room conditions. I can even say that my room was worse than the others. I didn't stay in a private room. I didn't want it anyway.* **Interviewee 32**

Although satisfaction with the physical conditions of single-occupancy rooms was high in general, the fact that the toilet was not reserved for personal use in the room possessed was a very important problem, especially for those who experienced isolation conditions with children. Reducing the number of people contacted was considered positive by the interviewees.

> *The first time I was hospitalized, the bathroom was in my room; but not when I was with the kids. It was forbidden to go out into the corridor. Going from the room to the communal bathroom was a huge problem. The little one is two years old, I used to leave him alone in the room; my older son had serum on his arm when I took him to the communal bathroom.* **Interviewee 13**

> *I was alone in the room. Only my nurse could enter my room and my doctor visited me every morning. Even at mealtimes, the cafeteria staff would not bring the food to my room. The number of people was diluted as much as possible.* **Interviewee 36**

The interviewees complained about the food delivery person who tried to leave the meal and go as soon as possible. They also expressed dislike of the food due to COVID-related loss of taste or because it did not suit their personal taste. They tended to force themselves to eat it though to keep their immunity level high.

> *I was disgusted when I saw the food, I couldn't smell it because I was sick. Even so, when the food was delivered, I had to eat it so that my immune system would be stronger.* **Interviewee 42**

> *You can't eat properly anyway; nothing has a taste. I even complained to the hospital saying that the food was terrible.* **Interviewee 24**

While the recommendations in the guidelines set the basic rules on this subject, regulations were made in practice according to existing or newly emerging conditions. Visitors were not allowed during the isolation of the patients, and they could only communicate with their family members through mobile phones (13). Patients were strictly forbidden to go out of their rooms. Hyun et al. stated that compliance with this ban was monitored by closed-circuit cameras in the corridors in their hospitals (18). The visitor ban, which was stated to be widely applied in hospitals, and thus seen as a practice that reduced mobility and crowdedness in the hospitals in the most effective way (13), was considered a negative situation by the interviewees. From the statements of the interviewees, it has been observed that the healthcare workers responsible for ensuring the implementation of the rules fulfilled their duties under the pressure of the authorities.

> *It's not an environment that we would approve of. The reason is that even visitors are not accepted. There is no one. The doctor, the nurses, the foodies, they're all dressed in white coveralls. The demoralization started slowly as no one could come to me during the time I was there. I said, 'Can't they be a little more moderate?' But then I thought they had a reason.* **Interviewee 33**

Abad et al. found that healthcare professionals, while giving direct care to the isolated patient, kept the time they spent in the room shorter than the patients who were not in isolation conditions, and they went to the isolation rooms less frequently. In addition, in some studies that they included in their review, using protective clothing and gloves when entering the patient's room was considered an obstacle for healthcare professionals and a step that made the work cumbersome (19). Kirkland and Weinstein revealed that the time healthcare workers attended patients in isolation rooms in the intensive care unit was half the amount compared to other patients, but the time spent in the room did not change (20). Saint et al., on the other hand, found that the frequency has decreased at the same level, and they also stated that only two-thirds of the patients in isolation were examined by a doctor during the morning visit (21). Short-term stays of health workers (nurse, cleaning staff, food delivery staff) in the patients' rooms by doing their job quickly and leaving as soon as possible upset patients who felt isolated from the outside world, had different levels of fear about the disease, and did not have many options to spend their time on. They experienced this negative effect even though they showed understanding. Nevertheless, the atmosphere of joy created by the little freedoms granted from time to time persisted for a while. Although there were cases to the contrary, the fact that doctors sometimes called and received information without coming to the patient's room affected the patients negatively. It was observed that physicians who stated that they did not behave in this way especially in their own professional practice were uncomfortable with this approach when they were in the patient role.

> *My only concern was getting out of the hospital. There was also uncertainty. Since no one was there, I constantly felt the need to talk. I'd been talking on the phone all night, but I wanted to ask the nurses something: They gave the medicine and left as soon as possible as if they were running away. Of course, they're right, they don't want to get infected, but that was interesting.* **Interviewee 13**

2. Patients' Preferences for Spending Time

Fan et al. made suggestions based on the findings of their studies aiming to investigate the needs of patients and their relatives and conveyed their arrangements in their practice. In this review, they emphasized that loneliness and boredom were the two most common emotional experiences, and they revealed that some of the patients relieved their boredom by watching television, but there was not a TV set in every isolation room, and those with a TV set complained about the limited channel options (13). Moreover, during the COVID-19 pandemic, comments are often observed that on television channels, discussion panels were made about the pandemic, reporting the disaster in the form of real or fake news, and the most complex and frightening aspects of medicine. Individuals who experienced any stage of the disease in different degrees of severity were negatively affected by having to listen to the worst possible scenarios in these programs or on their social media accounts.

Moore and March argued that losing social connections caused loneliness; and that it inhibited coping with problems in a healthy way. They indicated that there were two preferred methods to connect with other people during the pandemic: communication (e.g., by phone, messaging) and social media (e.g., Facebook, Instagram) (22). It was stated that during natural disasters, people's social support and social connections had a significant positive effect on health and that the disaster itself has triggered intense mutual assistance among people (23).

Among the activities interviewees preferred to spend time doing in the isolation room, watching television, talking, and texting with their relatives, watching social media posts, according to their interests, reading books, praying, trying to do their hobbies in the hospital room–perhaps as they do in their life outside the hospital were particularly mentioned. The determination of patients to continue their daily routine, as individuals who were generally independent before hospitalization, was a choice that will alleviate the feeling of being excluded from the rest of the world (13).

> *There was no alternative other than reading a book, yes there was a television in the room, but I didn't remember ever turning it on. It was also hard to focus.* **Interviewee 27**

> *I'm a person who likes to be alone, but after a while I get bored. Since I don't like watching TV, I took a few books with me, but I couldn't read the books when I had trouble breathing.* **Interviewee 11**

The psychological state created by isolation can often prevent focusing, sustaining, or diversifying these pursuits. Beck stated that television isolates and standardizes. He commented that regardless of where in the world they live or what class they are in, people gather in *the village square of the television* to consume the news (24). In fact, when it came to COVID-19 and its consequences, this collective consumption could lead to anxiety and rejection by the patients of the communication tools that were the source of such news, especially television. Isolation was also observed, in which the village coffeehouse was empty, and the patients confined themselves to communicating only with their close relatives.

> *As far as I heard, they removed the televisions so that the patients would not lose motivation and get demoralized. Thank God they didn't ban my phone. Our social circle is wide, may God be pleased with our friends; I couldn't keep my phone charged frequently enough. So, I did not understand how the time passed.* **Interviewee 30**

3. Isolation through Window and Wall Metaphors

Starting from the prison cell, the presence of a window and the transparency of the glass serve to shape the perception created by prison cell. Although the obligation of plague patients to open a window on the wall facing the street and respond to the inspection request by appearing there seems to belong to ancient times (8), the COVID-19 pandemic witnessed cases where posters with the details of the identity of the inhabitants were hung on the front of the quarantined house, and where the people under quarantine sent selfies (in a sense, exposing themselves by appearing at the window) to the nearby police station at certain times (25). However, there were multiple perceptions of the window/glass for recent interviewees hospitalized in isolation conditions in the hospital. It was forbidden to open the door, which was the only way in and out of the room they stayed in during their treatment and after recovery. To look *outside* – at the corridor – was forbidden by those who *supervised* the patients. On the other hand, the only physical connection point of the patient in the isolation room with the world outside the hospital was the windows; that was, the transparency of the glass showing the outside. While Foucault mentioned that the cell principle is turned inside out, he stated that only the first of the functions of confining-depriving of light-hiding remains (8). No patient was hidden in that room because the patient's presence there was known to both hospital staff and relatives, and even to strangers through social media, at the expense of their privacy. Since patients were visited for follow-ups at regular intervals, the light in the room might not be turned off at night, due to the importance of being visible in hospitals. The fact that these windows were not opened even though they let the daylight in without being opened made most patients angry because fresh air did not enter the room. It is frequently stated that artificial ventilation of air conditioners was restricted due to the risk of contamination. When viewed in this way, it seemed that the light and air, mentioned in the second function of the cell, have switched places.

Watching the people outside through the window provided both the possibility of not being among them again and the hope that difficult days would pass, as a rebellion against the deprivation that made them realize that they did not sufficiently appreciate the world outside when they were in it.

> *Nurses are coming, not talking to you. The doctor comes and talks to you from a distance. I felt very bad. I went to the window and watched the people outside. I said, 'I wish I could just lie down on the grass.* **Interviewee 38**

> *I only observed the outside world through the window. The fact that people who left work could go home after their work was finished, or that someone who came to the hospital for any reason could get the results of their analysis and return home with their child and spouse of their own free will, affected me even more negatively.* **Interviewee 2**

It was also the transparent glass barrier that allowed talking to the family members from a safe distance, without putting them at risk. At the other end of the glass impressions, there was standing by the glass and looking out, after the four walls of the intensive care unit, which is associated with heaven. The light from the window provided a general idea about the time whereas all sense of time was lost in the intensive care unit. Observing the details of the life outside could be a motivation that would facilitate adaptation when the interviewee went to the other side of the glass again. In any case, the presence of life could be discerned at the edge of the window.

> *After the intensive care unit, that room felt like heaven to me. Just standing by the window was enough.* **Interviewee 17**

> *The hard part of being in intensive care is that you are alone, and you sleep in a bed all day and night, disconnected from the outside world. Think of glass, like a prison. There is glass, but if you look to the right, there is a patient, if you look to the left, there is also a patient.* **Interviewee 47**

Concerning the modern confinement places, Foucault mentioned that everyone in them was confined to a prison cell alone, where they were seen from the front side by the supervisor. He then added that 'the side walls prevent these confined people from contacting their fellows'. The metaphor of the wall, unlike the window, does not have a double function. The wall has the function of creating a space according to the principle of individualizing framing (8). Indeed, patients hospitalized in isolation were aware of the presence of other patients in the next room only when their signs of illness were so severe that they penetrated the walls. Moreover, this situation could be perceived as the anxiety-inducing precursor of the clinical picture that the patient might come to experience. Consequently, it could lead to reactions such as trying not to hear those sounds (to cover up the signs), wanting to get away from that environment (the frightening possibilities of the future) as soon as possible.

> *There were two patients in the next room, husband and wife, who came in after me. I've heard really bad things. Horrible coughs, then gurgling, vomiting. I turned the TV up so I wouldn't hear them.* **Interviewee 1**

On the other hand, some of those staying in the hospital room, inspired by the fact that it was between four walls, described the place as a prison. As Foucault put it, “they are seen but they don’t see; they are an object of knowledge, but never a subject of communication” (8).

> *The mood is really bad because people come, and then they leave but you can't go anywhere because of the four walls around you.* **Interviewee 25**

Discussing the findings on the effects of isolation

The concept of *disease behavior* defines how people react to bodily symptoms and in which situations they take these symptoms to be abnormal. This concept includes observing people’s bodies, describing, and interpreting the symptoms of the body, trying to get well, and using sources of support besides official healthcare systems (26). In other words, the disease can be both the cause and the effect of people being influenced at home, at work, and in social institutions biologically as well as socially, culturally, and psychologically. Foucault states in the *Birth of the Clinic* that hospitals are ‘major institutions of confinement’ where patients are sequestered voluntarily. In each society, behaviors related to isolating the diseases medically and distributing patients to privileged and closed regions or healing centers, if convenient, depend on a choice system that is used to select, organize forms of aid, defy the fear of death, eliminate or alleviate poverty, intervene in diseases or let them take their natural course, for a community to protect itself and survive. Even though the behaviors mentioned here seem to be associated with protective medical practices at first glance, the emphasis on the *choice system* that follows may point to the domination of the minority by the majority (the ill by the healthy, the poor by the rich) over medicine. Foucault states that hospitals of a special stature that he calls *clinics* are places where patients must be included in a collective and homogeneous space to access information on the diseases because of a specific relation being established with experimentation. He also refers to the definition of the clinic by Bouillaud: “Medical clinic can be thought of as a science or way to teach medicine” (27).

Medicalization is a controversial concept used since the 1970s, which means making any phenomenon ‘medical’. Conrad refers to Zola’s definition as the most shortcut version: “It is a process of increasingly intense medical domination, influence and surveillance over daily life” (28). On the other hand, Zola states that integration of daily life practices and medicine had been expressed long before and that Sigerist (1945) defined medicine not only as a social science but also as a vocation that inevitably intermingles with society with most of its practices (29). Zola expands this function of the *medical system* defined for the first time in 1956 as ‘a social control mechanism’ by Parsons (9) to include many items such as gunshot injuries, suicide attempts, drug addiction, besides infectious diseases (29). Even though medical fields with social components are often thought to be mostly psychiatry and public health, today medicine has social components for many diseases.

The “patient role,” defined by Parsons, leads to individuals’ exemption from normal social roles depending on the nature and seriousness of the disease. The person who legitimizes the individual’s disease is the clinician who also calls the shots and has to cooperate with the patient to heal him/her (9). It is claimed that individuals have responsibilities to keep healthy and do what it takes to get healthy when sick and adjust their behaviors and lifestyle in favor of “what’s healthy” to maintain their social roles. Illich, who made harsh criticisms about the hegemony of medicine, talks about the concept of health as an autonomous, and not an instinctive reaction against socially structured realities (30). It is still culturally formed; and the ability to adapt to changes in the environment, to grow, and get old, to heal when hurt, to feel pain, and wait for death peacefully (9). Although keeping healthy is considered an individual responsibility, under circumstances of hectic work schedules and harm caused to the environment brought by social welfare or industrialization, it may be difficult to keep healthy. In extraordinary circumstances like epidemics, protective medicine, and medical treatment involve processes that require shared responsibilities with people as well as the participation of patients.

Protective measures such as *physical distancing* (31) mislabeled as social distancing, followed by social movement restrictions (lockdowns), schools closing, and mass quarantines, have been implemented pervasively with the prediction that hospital isolation would not be sufficient by itself. It has been stated that, in China, these measures were very strictly implemented; therefore, the number of patients decreased significantly, and there were no new patients even before the pandemic was declared (32). It’s been said that there were likely some asymptomatic people who were contagious or other people who had the virus in the incubation stage and went about their daily business in society (33, 34). For these reasons, for a pandemic with a fast-infecting virus, isolation in hospitals for patients, and isolation at home for the people who had contact with the infected have been recommended. Based on the cumulative knowledge and experience from previous epidemics, (35), most of the COVID-19 patients have been hospitalized and isolated very fast and worldwide. They were also questioned as to who they had been in contact with so that those people could be reached and tested. In our country, quarantine was implemented for people coming from abroad, albeit controversially; patients were treated under strict isolation in hospitals, schools were closed, including universities; social movement was restricted for those ages below 20 and above 65; general social lockdown and restricted intercity travel were implemented incrementally and periodically; hence the number of patients decreased at the end of three months.

New variants require the process to be renewed from the top. Foucault, who considers the birth of the clinic from a historical perspective, says “For clinical experience to become a form of knowledge, the sphere designated for hospitals needs to be reorganized completely; the social role of the patient has to be redefined; a certain relation has to be established both between help and experimentation and between help and knowledge.” Also, he states that patients must be dealt with collectively and in a homogeneous space (*clinic*) (27). During the pandemic, partly by following the scientific recommendations, and partly by a modification of the local organizational conditions, the treatment of COVID-19 patients has been done mostly by isolation in single rooms in hospitals, in adherence to a strict protocol. In the beginning, this was possible as the number of patients was relatively low. According to Illich, the reason why patients did not object to this was that the diagnosis isolated people in specific roles, separated the sick from the healthy, and hence made them obey the authority of the expert staff (30). Still, according to the concept of the sick role, it is stated that some patients prefer deferring their responsibility in such a situation even though they did not get sick by choice (9). On the other hand, the sick role is an important social control tool, and it can also be explained by the fact that it aims to bring back medical practices to the old social roles of patients (36).

In the context of the desire of “normal” (37, 38) to punish the sick, isolation can be considered a type of punishment for people who are deemed harmful to society due to contagious diseases. This is also seen in the background of stigmatization and exclusion behaviors. Foucault defines the situation where “the body, according to this penalty, is caught up in a system of constraints and privations, obligations and prohibitions” with a generalization of punishment method (8). During the interviews, some of the expressions used by the COVID-19 patients about the conditions they lived in at that time, isolated in their hospital room, are also included in this scope. However, it is not widely accepted to consider keeping the sick away from the healthy (39), which is undoubtedly a practice for the benefit of society, as a punishment in today's conditions. However, looking through this perspective at what those people have experienced behind four walls and closed doors can make the real-life conditions of insulation visible for those who prepare recommendation guides. While evaluating these conditions, the reason for choosing the penal-discipline axis is that among the major confinement institutions Foucault mentioned, there are mental hospitals, prisons, correctional institutions, educational institutions under surveillance, military units, as well as hospitals. It is argued that these institutions have dual-functions: binary marking (sick-healthy, for hospitals) and oppressive distribution (“how should it be recognized, where should it be, how should there be a continuous individual surveillance over it?” for the patient) (8).

In addition to the historic epidemics, the first thing that comes to mind is the plague, as the effects of the isolation experiences of centuries ago are examined. Those experiences have all been added to the collective memory. While discussing the practices of the ruling powers to maintain discipline through the plague, Foucault cites the horrors caused by the plague, just like riots, murders, desertions, people living and dying in disorder. He also states that excluding lepers by exile and enclosing the plague by lockdown have the same political ground (8). He argues that the plague, both as a real and an imaginary form of the disorder, finds a response in the form of medical and political discipline (8). The political aspect of the issue is related to surveillance. Foucault defines the obligation to open a window to the outer walls of the plagued people who are locked up in their homes, to respond whenever their name is read out loud, and to show themselves through the window when asked, as a “great inspection of the living and the dead” (8). Today, such a practice will be considered a violation of human rights. It is stated that the measures implemented in China in the form of electronic surveillance and physical control over society cannot be implemented by other countries, especially in developed democratic countries (40). Foucault argues that the order established through the authority via the lockdown and use of death as a threat in case of opposition to it functions to eliminate the confusion caused by the disease transmitted when bodies come into contact, and by the evil that would increase in the society when fear and death remove prohibitions (8). With the direction of the recent and remote past, the first response to a prevalent contagious disease in the community that turns into a pandemic was to quickly isolate people who had been tested positive or who were suspected of having contracted the disease from other people. As in previous outbreaks, isolation of patients and quarantine of those at risk of getting sick due to contact have been carried out with similar rules since the beginning of the COVID-19 pandemic.

This study reveals the social effects of patients diagnosed with COVID-19 and treated under isolation in hospital, because of a multidimensional evaluation, as experiences from different fields, each of which is a striking component of that social phenomenon. It is of great importance that the prominent ones being evaluated in such a way that offers a solution or a perspective for the future.

Since the first day of the COVID-19 pandemic, this study was made possible because the researcher, together with other colleagues, is a physician who fought the pandemic with a professional reflex. Also, she had started to do a master's degree in sociology just before the pandemic, which helped the study. While experiencing the fever of the pandemic in this rapidly transforming professional practice, encountering the clues of some social and psychological effects in the short-term interviews she made with the patients she served in isolation rooms form the basis of the research. When sociological infrastructure, which reinforces the focus on the social components of health was combined with the opportunity to access these patients, a Weberian “call to duty”, vocation, (Beruf) (41) has emerged. The originality of this research stems from the fact that it is a study that focuses on discourse analysis, while holding a mirror to the individual experiences, and recording the reflections in the way the individuals chose to express. Thus, it was possible to discover a wide range of experiences.

Protocols for the regulations related to COVID-19 pandemic is mainly based on the lessons gained from previous epidemics even though they were not globally effective. Scientific information mostly originated from perspective articles and survey studies determine the social problems caused by previous epidemics. Nonetheless, similar preventable problems continue to be experienced in the COVID-19 pandemic. There is no other study in the literature investigating isolation context, especially with the qualitative research technique using in-depth interviews via patients. Being a doctor might naturally give a confidence to talk about health and illness in professional way and an ability to manage health issues raised during the interviews with the patients. Additionally, being a sociologist might naturally give the enthusiasm to see the sociological perspective behind the medical issues.

Although isolation of patients is a necessary precaution in terms of preventing contamination, it is important to start from the experiences under isolation when determining their conditions and planning for the support to be given to patients under isolation. These include considering the social and psychological needs. When doing these, it is important that the healthcare professionals, who enter the isolation room by taking protective measures, would approach the patient according to the principles of effective patient-physician communication; and the arrangements would be made to meet the needs of the patients such as spending time, communication with the outside world, and logistic support.

In conclusion, this part of the recent study demonstrates the need for considering and resolving the adverse effects of confinement-like measures for the future pandemics since patient isolation and quarantine of at-risk people will continue to be used as an effective infection control measure.

PART II.

New Stigma Archetypes and Self-exclusion Propensity in COVID-19 Patients

The stigma in COVID-19 has been described by Sotgiu et al. as a worldwide “witch hunt” hysteria, and it is claimed that it creates grounds for discrimination and attacks on vulnerable people (7). At the end of their article, it was stated that, from the beginning of the pandemic, the Chinese have been stigmatized, and racially discriminated against all over the world. Viruses were shown as an example to people as viruses would not discriminate based on race, religion, belief, gender, or sexual orientation; and it has been recommended that people fight the virus, not each other, by giving a message of unity (7). The rate of spread of the “Chinese virus” stigma on social media has been demonstrated to increase 10 times between 9-15 March and 19-25 March tweets (42). Stigma and exclusion behaviors towards patients spread around the world at least as fast as the virus but failed to draw attention at the same rate.

It is not always easy to differentiate between social exclusion and stigmatization conceptually as well as a component of perceived identity. Link and Phelan stated that when people are labeled, kept away, and associated with undesirable features, justifications are produced for devaluing, rejecting, and excluding them (43). Individuals classify distancing behaviors towards themselves according to how they perceive them, while naming them as exclusion. Exclusion behavior is often based on an act of stigmatization that would discredit the person targeted. In addition, preventive measures may include avoidance behaviors based on the need to avoid contact with potentially contagious persons. In the case of infectious diseases, such as COVID-19, which can be transmitted by people who do not show any symptoms, anyone encountered can be included in this scope.

In the article that summarizes the systemic struggle during the first week of the SARS epidemic in April 2003, it was stated that Asian-Americans were exposed to stigmatization and discrimination way more often; therefore, they had a culturally tailored intervention for this ethnic community (44). We need studies that demonstrate the effectiveness of methods recommended and practiced in fighting stigmatization. Heijnders and Van Der Meij suggested creating awareness in terms of human rights violations encountered by affected individuals because of actively participating in social life as part of *the struggle against stigmatization* (45). As being a first time experienced contagious disease, COVID-19 should be considered in relation to its effects on stigmatization.

This part of the research, under the purview of health sociology, aimed to contribute to studies related to health/illness and to concretize individuals' behaviors and rituals as institutionalized patterns using qualitative research methods. The main theme of the research has been determined as *symbolic interactionism* as far as integration was concerned. Especially in micro-social aspects, daily life, ways of interaction, the way order and meaning were created, and the main factors driving people aimed to focus on.

Findings

A significant portion of interviewees with a diagnosis of COVID-19 experienced stigma and exclusion related or unrelated to it. To distinguish whether the behavior is stigmatization or exclusion, the stigma must have a discrediting (at the level of individual's perception) quality and/or refer to one of the archetypes known as stigma. Although the question posed to the interviewees was aimed at learning about their encounters with ostracism both in the society and in the hospital environment, the findings were discussed in two groups as stigmatization and exclusion experiences, because of the separation of the responses received with this approach.

1. Stigmatization Experiences of COVID-19 Patients

These experiences of COVID-19 diagnosed individuals exposed to stigmatization were discussed in different sections of social life (social environment, family environment, health institution, family) and components of the concept of stigma (stigma symbols, stigma archetypes, individual reactions, solution suggestions). Their stigmatization in social life began while they were still treated at the hospital. For a stigma to occur, the diagnosis of COVID-19, which was the subject of it, had to be heard. The diagnosis known by others was discussed in detail in the section dealing with the issue of privacy (in the next part). In summary, although there was no physical sign of the disease, it was frequently mentioned that the diagnosis in question was not only heard by other people with or without the knowledge of the patient but also that it spread. Since the number of patients at the time of the study was relatively lower than in the following tides (46), the interest and curiosity of society may have been more intense back then. Almost all the patients had been hospitalized in isolation conditions. So, they suddenly had to move away from their social roles, and their household had to be put under quarantine. This way, their workplace, and social circle might have become aware of the presence of this disease.

The stigmatizing behavior faced by interviewees, especially in connection with their profession, carried the risk of affecting their current and future business relationships. This possibility could be predicted through the consequences of stigma, such as loss of social status and disrepute. Individuals and family members stayed away from their jobs in the private sector or their own business during hospitalization and then quarantine periods, which might financially affect them. This negative effect might last longer due to stigma. The stigmatizing behavior in question could be done on social media by people whom the patient knew or by strangers; this behavior was independent of these people's educational background. It also put the person in question into a difficult situation and upset them. While dealing with the problems caused by the disease, also trying to cope with the problems created by such social interactions could become inextricable.

> *Which ones will you cope with? It's not one, not two, not five, or not even ten. So, you let it go, your priorities change. Our laws against these actions are not strict enough, either.* **Interviewee 22**

While the families of the patients generally did not stigmatize/exclude, there might be exceptions to this. However, stigmatization by neighbors and close friends might cause difficulties and force people to present evidence related to their health status. Thus, it was preferred to go to another place, to get over the process by staying in a rental house or a relative's house until these situations blow over, but it was not always possible to find such a house.

> *People were scared when you said, "I have COVID". It's like we were the boogeyman.* **Interviewee 42**

> *Neighbors are still saying "Run away from the person with Corona". Son of one of them is young, five or six years old, and he says, "She has Corona, run away".* **Interviewee 48**

> *We thought we'd find a place to rent for fifteen days of the quarantine. I have clearly stated the situation. There was no positive response from any real estate agent. You don't stand a chance, even with money.* **Interviewee 27**

Although it was noted that patients experience stigmatization behavior in the hospital from some health workers, it was observed that patients receiving healthcare under isolation conditions usually described the behavior of health workers in positive terms, as discussed in the relevant section (in previous part). Since the aim of this section was stigmatization, only examples in that context were included here. In addition, the experiences of health workers were discussed in the exclusion section. Some healthcare workers who got sick stated that they experienced a privileged situation compared to other patients in terms of stigma. A study conducted by Eren-Bana in Turkey with 151 participants using a questionnaire shows that 51.2% of healthcare professionals experienced stigmatization (47). In addition, Ergur et al. studied with physicians and nurses involved in the fight against the pandemic, it was stated that besides the close social circles of the patients, exclusion by those colleagues who did not attend to COVID-19 patients was more common than the stigmatization behaviors seen in the historical process (48).

Bagcchi, in his article showing the stigmatization faced by health workers in different countries, stated that doctors and nurses were forced to use bicycles in some countries as they were banned from public transport, and were exposed to physical attacks, harassment, and insults while performing their duties in public places. They were also evacuated from their rental apartments (49). Also, Singh and Subedi cited the behavior of some individuals and some healthcare professionals working in non-COVID services as examples. They refused to talk to and to eat in the same cafeterias as the healthcare professionals working at the forefront of the pandemic. They also stated that their neighbors expressed dissatisfaction with their residence in their apartments although they took all the necessary precautions (50).

It was possible to see similar situations in the statements of healthcare professionals interviewed as patients. In addition to the expressions exemplifying the stigmatizing approach of the community members, it was observed that the health workers exposed to this behavior from their colleagues have been disappointed and sad.

> *The hospital environment is really bad. A colleague from the surgical branch refused to work on COVID patient from the beginning of the pandemic. When he saw me even before I was sick, he shouted among all the patients, "You are full of viruses, get away from me".*
> **Interviewee 27**

> *In this process, they said that "buses are free for healthcare workers". But when you show your health card and get on the bus, other passengers stayed away from you. You know, it was just like when they left lepers on an island.* **Interviewee 29**

Among the stigmatizing diseases, mental health problems and social effects on the families of the patients are frequently studied. Studies that are conceptually analyzed as *family stigma* not only guide future research but also contribute to improving the healthcare given to families. The last of the three basic descriptive features presented in Park and Park's article involves the belief that all the family members directly or indirectly contaminated by the sick person (called problematic in the article) are harmful, dangerous, and unhealthy. It includes the belief that they may have negative effects on other people, or that they deviate from the general social norms (51). Due to the rapid infection of the disease, the families of people diagnosed with COVID-19 might also be stigmatized.

In connection with the fact that family members are also exposed to stigmatization, *infected family* stigma has entered the terminology specific to this disease. In cases where patients are stigmatized, family members and even relatives who do not live in the same house are frequently stigmatized. This situation may push individuals to resort to lies to avoid stigmatization. In recent study, it was observed that in families who have quarantined themselves at home, the children and family members in other households of the family building were also stigmatized. These people stated that they were exhausted as a family due to the reactions of their neighbors with irrational concerns about contamination.

> *Before and after hospitalization, I was treated as if I had the plague and as if I would never get better. During our stay in the hospital, my sisters-in-law also experienced some difficulties. For example, when children went to the grocery store, they said, "Don't come in. Your family has the virus" They throw out the baby with the bathwater.* **Interviewee 51**
>
> *Neighbors, especially when they saw my children, covered their mouths, saying "Aren't you the children of those COVID-19 parents?" They hurt my children's feelings.* **Interviewee 28**

While speaking of stigma symbols, which he defined as the opposite of reputation symbols, Goffman stated that they are quite effective in drawing attention to a humiliating identity mismatch by breaking up a picture that might otherwise be coherent. (37). Bruns et al. stated that researchers were careful to avoid any stigma when naming this virus [COVID-19 agent, SARS-CoV-2 or the new Coronavirus] (35).

Among the statements of the interviewees, there were some stigma symbols that have not been used before. These symbols have been used specifically during the pandemic, frequently in proportion to the number of patients. In the hospital, COVID-19 patients were transferred from the emergency room to the inpatient service, between the intensive care unit and the inpatient service, to the departments to be examined on stretchers or wheelchairs with a plastic cover to provide insulation for transportation (Figure 2). When these transfers were carried out with the corridors full of patients, their relatives, and healthcare workers, this protection measure taken to prevent the spread of the virus became a visual stigma for the patients. This caused other people to notice clearly that a person with a contagious disease was passing by, so it negatively impacted the patient transferred by a different stretcher or chair. In addition, a sick hospital worker with that stigma passing through a group of people he/she knew added another dimension to the situation in terms of the way they were greeted in the community upon their return there after recovery.

> *While they brought me to the room from the intensive care unit, they had covered the stretcher with plastic. People in the hallway looked on as I was on that stretcher. I felt very bad at that moment.* **Interviewee 4**

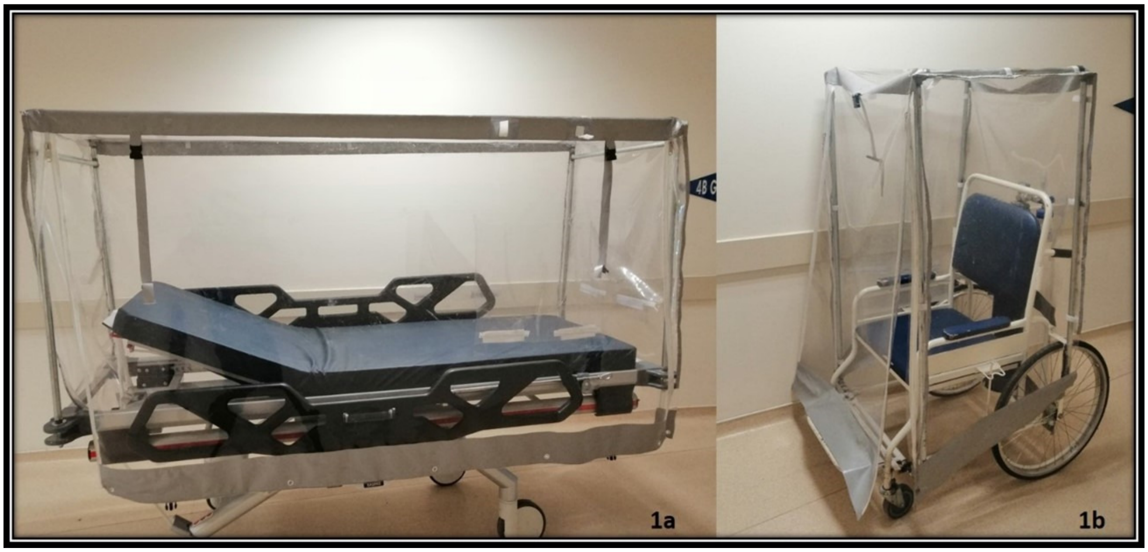

Figure 2. Transparent cover transport vehicles used for the isolation and transfer of COVID-19 patients within healthcare facilities. 1a. Patient stretcher and 1b. Wheelchair

Another stigma symbol has been the ambulance. Being taken from the house by ambulance, especially when it coincided with daytime or when people were awake in the nearby houses, led to stigmatization with COVID-19, due to the conditioning of the pandemic conditions. When people went to a health institution with symptoms, they were recommended to wait at home for the result after the microbiological test was performed since the test takes time. If the result was positive, they were told either to go to the hospital by themselves or that they would be taken from the house by ambulance. Some experiences include the ambulance coming in front of the house and the patient getting on it and going to the hospital –while feeling the reactions of neighbors and passers-by. In extreme instances, the intercity bus with the patient was stopped by the ambulance and police car, and the patient was taken among the reactions of the other passengers on the bus; or the patient was taken from the house among confrontations and conflicts from the nearby balconies.

> *When they came by ambulance to quarantine me, the passers-by looked through the windows of the building opposite. It hurt me a lot. This left a mark on me. When everyone looked at me like that, I thought, it's like I committed a disgraceful crime.* **Interviewee 39**

COVID-19 patients were also exposed to stigmatization and ostracism by healthcare professionals in the hospital setting. Some interviewees stated that there were good and bad examples together, due to personal differences. Some tolerated these reactions from healthcare workers, as they thought these were self-protective behaviors.

> *It's about being a good person or a bad person, no matter what you do in life. Some nurses came in and they were rightfully scared. It's a very scary disease. They treated me very well. Whereas some see you not as a person but as a virus.* **Interviewee 35**

> *They stand far away. It's like I'm a bogeyman. It really affected my mental health. When my test turned negative, all their expressions changed.* **Interviewee 20**

It is observed that while stigmatizing experiences related to COVID-19 were conveyed, the names of diseases, which were generally referred to as health-related stigma archetypes, were used by the interviewees. The nomenclature "like a leper, like the plague" was frequently used by the interviewees. Goffman described the ranking of stigmatized individuals among different stigmas as "the ability of the stigmatized individual to adopt the same attitude that normal people take towards those who are more visibly stigmatized" (37). However, instead of diseases such as tuberculosis, HIV/AIDS, and mental illness that continue to exist and stigmatize people today, some often chose diseases of the past such as the plague, or leprosy, another curable but not contagious disease, or even a supernatural adjective such as “boogie”. The reason for this may be that they do not want to associate themselves with a current and real health problem that will go beyond their current experiences. Another possibility is that people stigmatized by COVID-19 might reflexively show a similar stigmatizing approach to these archetypes. In addition, the selection of outdated leprosy and plague stigmas may be due to the desire to add a mystical air to their experiences. While an interviewee, who was a healthcare professional, criticized the person who stigmatized him because of his illness, he stated that the spouse of that person works in a riskier area.

> *Everyone is afraid of us, like lepers.* **Interviewee 23**
>
> *I inevitably felt uncomfortable when people stayed away and talked as if I had the plague.* **Interviewee 30**

Theories and research that deal with the stigma perspective show that individual structures have a key mediating role in stigma responses (52). In addition to exclusion from society, avoidance behavior can also be demonstrated, depending on individual perception of humiliation, shame, and guilt. In order not to be stigmatized, different attitudes and behaviors can be displayed to hide the disease as well (37). Individuals who are negatively affected by people's stigma and exclusion continue to hide or even deny that they have had the disease. Concerns about the negative impact on the job, and therefore economic conditions, have an important place among the reasons for choosing to display a deceptive appearance. On the other hand, an interviewee stated that he was warned to hide his illness –by the person who transmitted him the disease– even before he experienced this situation, but he predicted that his job would be positively affected because he has already had the disease, and this would create confidence. This indicates that rational choices have been made between the two possibilities. When the stigma behavior comes from those outside the family but from the close social circle, especially the neighbors, the illness was hidden from them. For these reasons, individuals were concerned about the damage to the relationships they established before the illness. It was observed that, after daily encounters caused him to panic, an interviewee explained the substantial loss of weight due to the illness because of a diet. So, he switched from deceptive behavior to lying.

> *The person who infected me said, "Don't tell anyone you had COVID because your career would be over."* **Interviewee 40**

> *I did not tell anyone in the building that I was in the intensive care unit, that I had COVID. When I see someone who says, "Why did you lose weight?" I say, "I had a good diet". I don't talk about COVID.* **Interviewee 47**

After the illness, the stigma anxiety continued. An interviewee who was exposed to stigmatizing behavior in the family during his illness continued to stay away from his relatives, thinking that he would be blamed even if someone else infects them with the disease.

> *People are afraid of getting COVID because of stigmatization more than dying because people exclude you so much. Someone committed suicide here.* **Interviewee 40**

Stigmatization, in addition to the stress and sadness caused by the disease, causes negative psychological effects. The understanding shown against exclusion behavior was not seen in this regard. Denial and self-defense were encountered when the feelings due to these behaviors, albeit rarely, were conveyed to the neighbors who were the addressees of the incident.

In the literature, it is mentioned that there is a need for studies investigating the effectiveness of solutions to stigmatization. Societal, organizational, and individual multidimensional recommendations are made regarding stigmatization in tuberculosis and HIV/AIDS (53). The suggestions among the statements of the interviewees generally included raising awareness of the society.

> *It would be a little different if we could make people believe that it is just a disease and that if the necessary precautions are taken, it will not harm anyone else. I think that exclusion would decrease then.* **Interviewee 22**

2. Social Exclusion Experiences of COVID-19 Patients

Most of the answers given by the interviewees to the question of whether they encountered exclusion behavior revealed a remarkable situation after discharge: self-exclusion behavior. There might be different reasons for these choices to strictly distance themselves from people and, in a sense, exclude themselves from social life. These included protecting others by not wanting them to experience what they have experienced during a contagious disease or taking care of themselves out of concern that having experienced it once would not prevent them from getting it again. On the other hand, Goffman states that it is possible to avoid the obligation to share information that affinities will bring about, because of the voluntary protection of various forms of distance (37). By shutting themselves at home, people could avoid interactions with others who did not know about their illness background and who might record it as part of the recovered person's biography. Worrying that having had an illness could be a cause of humiliation and discredit might be a reason for trying to share this secret only with family and friends and prevent others from learning about it. A situation that supported this view was also commonly observed in the statements of the interviewees: Spontaneous disclosure. According to Goffman, voluntary disclosure is one of the signs of a moral career and is described as a state of peacefulness (37).

The number of interviewees who announced their illness to their social circle and then applied absolute isolation at the expense of extending the quarantine period was not small. In this choice, especially the anxiety of harming people around them was effective. Even if the exclusion was self-inflicted, it caused sadness in individuals. Still, this approach seemed to prevent ostracism from other people. On the other hand, it was observed that those who did not want people to come to their home, avoid meeting them, including their closest relatives, and apply protection measures without compromise, almost never experienced exclusion.

> *Frankly, I mostly isolated myself from people because I was afraid of hurting someone.* **Interviewee 46**

> *I told my neighbors about this. I specifically reported it to our concierge. They never excluded me. They didn't make me feel bad.* **Interviewee 4**

The exclusion by a group of people who were in the majority due to at least one common feature in the society (who did not get sick and/or who did not have anyone in their close circle who got sick) of the people who were in the minority (patients and/or people who got sick in their close circle) with humiliating words was one of the exclusion behaviors that COVID-19 patients were exposed to. Among the reactions to this situation, loneliness and isolation, and sadness caused by being treated like this by their closest relatives were at the forefront. In addition, people evaluated such experiences as an opportunity to get to know their true friends, to cut off relations with those who exhibit this behavior, to even feel grudge and anger, to resort to humor, to hide their situation so that more people do not learn, and they “protect the privacy by exercising something other than tact” (37).

> *I have been ostracized by neighbors, friends, people around me. So, I cut them out of my life.* **Interviewee 40**

> *I did not share that I had this disease with anyone until I recovered, I did not talk about it so that it would not affect my psychology.* **Interviewee 20**

Just like stigmatization, children and family members of sick people were also affected by exclusion behavior. Although there was more than one patient from the same family, family members could not be protected from the effects of exclusion behavior in unity since the patients were still in the minority in the society at that time. Patients' statements included the exclusion that their children and family members were exposed to, a situation that upset them more than their exclusion. Even if people could apply coping mechanisms against the behaviors directed at them and develop strategies to manage information –*passing* in Goffman's words (37)–, they still felt helpless in the face of the influence that extended to their environment.

> *I had a bit of trouble mostly because I was separated from my children. The approach of the people against them made me very sad; otherwise, I didn't have any problems.* **Interviewee 28**

It has been observed that healthcare worker interviewees were ostracized by their colleagues in their hospitals, and by other people, such as relatives, and even family members before and after their illness. On the other hand, the illness of healthcare professionals could be tolerated, albeit rarely.

> *You feel excluded because of your profession as you specialize in pulmonary diseases, even if you don’t get sick.* **Interviewee 27**

> *As I am a healthcare worker, the neighbors were very happy to see me because it is seen as an occupational disease. They may be angry with others, perhaps because they think those people were not careful outside.* **Interviewee 32**

Although patients were generally satisfied with the approach of the healthcare professionals during their hospitalization, it has been observed that some interviewees felt excluded by the healthcare professionals. Still, most people regarded this as natural self-protection efforts of healthcare professionals who had to deal with a contagious disease. On the other hand, the differences in the approach and style of the healthcare professionals determined the perception of that attitude by the patient. The evaluations of the interviewees regarding the approach of the healthcare professionals varied from seeing it as an obligation of the profession, without excluding the patient, accepting it as reasonable behavior, evaluating it as signs of professional ethics, and love, and giving positive and negative examples of their style. Also, statements that underlined the importance of moral support were frequently encountered when healthcare professionals approached the patient without any exclusionary behavior while dealing with them.

> *It was obvious that the gentleman was afraid of me, but I couldn't do anything about that. Of course, they are scared, I get it. So, that day I said to him, "I understand your position, but this is your job. You got trained for it. You need to do it no matter what. No matter a virus or no virus."* **Interviewee 44**

Like the interviewee who claimed that the most striking result of the study would be on this issue, other interviewees stated that a bigger problem than the disease was exclusion. Many interviewees stated that healthcare providers were in a hurry to leave the room as soon as possible without communicating with the patient after performing their primary duties such as giving medicine, measuring temperature, and bringing food, so they considered these among the experiences of exclusion they have experienced. Especially in the intensive care unit, the negative effect of exposure to this approach was emphasized. In addition, the support to be provided by frequent phone calls was considered important for healthcare professionals or their relatives, even if the patient could not be visited.

Discussing the findings on stigmatization and self-exclusion

As Goffman first defined it in 1963, the concept of stigma is used in social sciences as "an adjective that is undesirable or discredits the individual's position in society". On the other hand, Goffman underlines that what is needed is not a language of adjectives, but a language of relations (37). Thus, the concept settles on a spectrum shaped by mutual behavior and attitude-based interaction between people and humiliating discourses. Courtwright stated that stigmatizing someone was not only a response to unwanted threats from that person but also labeling that person in such a way that would cause them to view the threat as undesirable. This situation also revealed feelings of shame and self-hatred in the stigmatized person (54). Parker and Aggleton proposed to consider stigma as a social process that people used to exert social control by polarizing other people into “normal” and “different” out of fear of illness (55). As can be easily interpreted, the normal ones mean “we”, the different ones mean “they, the outsiders”. It can be said that stigmatization builds a wall between these artificial groups. Becker's conceptualization of stigma, on the other hand, refers to a person who commits an act socially determined to be sanctioned as a *deviant behavior* in case of violation. The person stigmatized by this gaze is the one to whom this label has been successfully applied, as a deviant (56). Together with the discrimination it causes, this situation serves to increase social inequalities. According to Heijnders and Van Der Meij, stigma, shaped and declared by institutional and social norms and interpersonal attitudes, is a social marker of health (45). On the other hand, it is argued that stigma should be seen as an important topic in terms of philosophical reflection since it is not only related to inequality in access to resources (54).

After Goffman's conceptualization, based on his observations, varying definitions were made for different situations, and there are many examples of this in the literature. The fact that the same concept is handled with different definitions is attributed to two reasons. The first is that this concept is used for a wide range of situations, each of which is unique and needs to be handled in different ways; and the other is that stigma, which is examined in a multidisciplinary way (psychology, sociology, anthropology, etc.), is based on different theoretical orientations between disciplines and even within each discipline itself (43). Although there are different ways of dealing with stigmatization, not paying attention to the discourses and perceptions of the people affected in terms of a health problem ultimately leads to misunderstandings and incomplete evaluation. In addition, defining stigma based on features rather than relationships is because the said stigma or sign is seen as a state that is owned by the person rather than one that is attributed to that person *by others* (43). According to Courtwright, for stigma to occur, unlike the exclusion component of discrimination, the stigmatized individual must feel shame and guilt, that is, internalize the stigma (54).

Labeling, stereotyping, loss of social status, discrimination and exclusion are among the components of stigmatization behavior. These components is listed as follows: an individual's ability to distinguish and label human differences; labeling undesirable qualities of individuals with negative stereotypes due to the beliefs of the dominant culture; loss of social status and discrimination leading to inequality; and exclusion of labeled individuals in different degrees from “us” to “they” by placing them in separate classes (43). Deviant behavior is determined not by the actor, but by the exclusionary behavior of a community that calls it that. Thus, while *we* are defined as a community of “normals”, a deviant person or group of people outside this definition functions to show what the norms are; and they are defined as *them,* and excluded from common belonging (56). These perspectives may contribute to the positioning of the two concepts concerning each other.

Considering the literature on the subject, the most prominent analysis is that these differences of the stigmatized individuals in the minority are deemed undesirable and degrading qualities by the majority who do not have the stigma. Then, by various forms of labeling, exclusion, and discrimination towards those individuals, they experience loss of status and inequality. Moreover, if the labeled individual internalizes this approach, the negative consequences of the experience increase with the feelings of guilt and worthlessness. Many people are heavily affected by the health-related stigma and discrimination they are exposed to because of their illness. The diseases most frequently studied for causing stigma are HIV/AIDS, mental disorders, substance abuse, leprosy, tuberculosis, and epilepsy (45, 57). In this context, to take effective measures, it is important to determine whether there was stigma or exclusion in the context of COVID-19, and if so, its nature and degree, based on other health-related examples.

As a result of the lessons learned from historical epidemics, which are generally applied to infectious diseases, it is suggested that stigmatization should be viewed as a bio-social phenomenon because of its four important components: 1) Stigmatization can create major barriers to healthcare attempts. 2) Social isolation can often lead to poverty and neglect. 3) Communities likely to be stigmatized may challenge health authorities and resist cooperation in public health emergencies. 4) Social stigma can distort the public's perception of risk, leading to a mass panic among citizens and improper allocation of health-related resources by politicians and health professionals (58). Stigma is conceptually different from discrimination, which is another social determinant of health. The latter has the purpose of excluding without inducing shame or guilt (53).

Stigmatization and exclusion of healthcare workers were common throughout society during the pandemic. One study on this topic is about stigmatizing healthcare workers as COVID-19 contaminators and avoiding them. In a study conducted with 3551 non-healthcare workers using questionnaires sent over the internet, more than a quarter of the participants expressed the opinion that restrictions, such as isolation from the society and their families, should be applied to health workers; and one-third of the participants avoided health workers due to fear of infection. It has also been revealed that those who showed stigmatizing and avoidance behaviors separated altruistic supporting behaviors towards healthcare workers (such as clapping at windows in the nights) from these exclusionary opinions; and that those who showed stigma and avoidance behaviors were also hesitant to go to places such as pharmacies, supermarkets or even leave their homes. In the end, it was argued that these findings were associated with the COVID Stress Syndrome and that if they could be prevented, stigmatization and exclusion of healthcare professionals could also be prevented (59).

It is not always easy to differentiate between social exclusion and stigmatization conceptually as well as a component of perceived identity. Link and Phelan stated that when people are labeled, kept away, and associated with undesirable features, justifications are produced for devaluing, rejecting, and excluding them (43). Exclusion behavior has also been experienced in outbreaks prior to the COVID-19 pandemic. In a study that looked at the post-quarantine exclusion experiences of people quarantined during the SARS epidemic, 51% of respondents found that people avoided them after the quarantine, 29% were not invited to social events, 7% were not sought after by friends, and 7% said that their family members were not invited to these meetings because of them (60).

The COVID-19 pandemic is not the first major epidemic in human history, nor will it be the last. Although there are many scientific articles to determine the social problems caused by previous epidemics, similar preventable problems continue to be experienced in the COVID-19 pandemic. Sociological issues such as anxiety, privacy, stigmatization, isolation, economic factors, and family relationships in society and patients, researched specifically for COVID-19, are presented in the form of reviewing or reporting previous articles (e.g., 13, 15, 35, 61). There is no other study in the literature investigating these issues, especially with the qualitative research technique.

A remarkable observation of this study was the “self-exclusion” behavior in patients. There were signs in the statements of the interviewees that an altruistic attitude in a contagious disease was a very common behavior. A general observation was that ostracism and stigmatization were less common in cases where voluntary disclosure was available. Still, whether the self-exclusion behavior has an effect in this direction should be clarified with new studies.

COVID-19 created new stigma archetypes and negatively affected patients and their relatives. The knowledge on infectious diseases such as tuberculosis, HIV/AIDS, supported by qualitative research, seems to have made the subject reflected in the guides (53, 55, 62, 63). It is important to prepare similar guidelines for COVID-19 and to conduct qualitative research to provide a basis for them.

In conclusion, this study demonstrated the importance of rethinking some sociological concepts such as stigmatization and social exclusion in terms of the specific properties of COVID-19. It is also very important in terms of future experiences to take precautions against adverse effects of stigmatization and exclusion.

PART III.

The Privacy Violation Experienced by COVID-19 Patients

Since our knowledge about the cascading and inclusive effects of COVID-19 on almost every aspect of both individual and community life accumulated owing to scientific studies. The aim of this part of recent study was to evaluate the approaches to privacy, under the purview of health sociology, and to contribute to studies related to health/illness and to concretize individuals' behaviors and rituals as institutionalized patterns on the privacy either respect or violence perspective.

An article published in a legal journal that evaluates the differences in what is meant by the term “privacy” in everyday language is quite noteworthy. Gavison stated that the concept of privacy was consistent and useful in three contexts. He defined these as the loss of privacy, the invasion of privacy, and the actionable violation of privacy, each being a subset of the previous one (64). These categories are considered contexts that can guide the evaluation of forms of attacks on privacy. The first context defines privacy as a neutral concept, as it helps to demonstrate that a person's privacy barrier has been breached. The invasion context views the protection of privacy more as a social value, involving the claim that unwanted situations are responsible for the loss of privacy. The final context is positioned to determine which situations require legal protection since the law cannot address all unwanted situations. Gavison's definition of privacy is both brief and comprehensive: “It pertains to our accessibility to others; the extent to which others know us, can physically approach us, or how much attention we draw to ourselves, with the loss of our privacy becoming noticeable when a boundary is crossed” (64). The ambiguity in the definition and the step of seeking legal recourse perhaps stems from this boundary not being sharp, its expandable and contractible nature depending on different individuals, and the tendency of people to predict their own boundaries based on those of others.

The social atmosphere created by the pandemic has changed the perception of the concept of privacy; because, as Durkheim states, when anomie (normlessness) is in question, “The relationships between different segments of society are inevitably altered, so the ideas that describe these relationships can no longer remain as they are” (65). The levels of privacy loss experienced by patients, ranging from invasions to even actionable violations, were generally met with helplessness by those who experience them, and perhaps for this reason, the choice to consider them as a normal situation was frequently observed.

Due to the subject of privacy, it is inevitable that ethics, particularly medical ethics, and legal discussions occupy an important place during the research. From a sociological perspective, in the context of *Symbolic Interactionism* theory, the focus is especially on the micro dimensions of society, daily lives, the contemporary everyday world in which people live, how individuals are influenced in these lives through *symbolic communication*, how they create order and meaning, and the fundamental factors that motivate people regarding a particular situation. In this way, starting from the individual's experiences of losing and regaining their bearings, it is anticipated that the disintegration and reassembly of society as a response to an extraordinary situation, thus making the envisioning of society amid uncertainty possible.

The personal observations of the researcher, who also worked as a specialist in chest diseases, have drawn attention to the sociological aspects of the hospital stay and post-discharge periods in patients diagnosed with COVID-19. These included the negative effects of isolation, stigmatization and exclusion approaches, and the normalization of privacy violations. The impacts related to privacy fall under the responsibility of both health and social sciences at the intersection of medical ethics. Physicians' adherence to the ethical principle of protecting patient privacy can vary individually. When it comes to an infectious disease, the rationale for unethical behavior might be the justification of protecting society, the patient's environment, and healthcare workers from the infectious disease. Another aspect of this issue is that, besides being stigmatized by society, patients may also face stigmatization and exclusion by healthcare workers within health institutions. Traditional and social media are examples of environments where privacy violations most frequently occur. When appearing in the media is a voluntary decision of the individual, it is natural for there to be personal reasons such as wanting recognition, believing they have something to say and wanting to share their knowledge, skills, or experiences with a wider audience. On the other hand, it is important to consider the impact on individuals who do not have such an inclination but suddenly become known to large crowds due to the multiplying effect of the media, especially when this recognition is based on information about their illness rather than other attributes they might prefer, which can potentially fuel stigmatization, exclusion, and discriminatory behaviors.

How ethical issues are addressed in extraordinary situations provides very important evaluation clues for that community. Regarding the ethical issue of privacy in the context of the COVID-19 pandemic, it should serve as a ground for rethinking, reviewing, and making recommendations. Otherwise, like many other concepts, its scope would change, leading to various problems for individuals compared to previous periods and resulting in the transformation of society. Therefore, examining the perspective on privacy through the ways in which the condition of infected individuals was disclosed to others during the pandemic would act as a magnifying glass, offering the opportunity to evaluate the general approach to ethics in society and the reasons behind it.

Findings

During the initial months of the COVID-19 pandemic, the experiences of interviewees, who drew public curiosity as patients, regarding respect for their privacy or privacy violations were addressed within the contexts of the impact of media environments on these experiences, occurrences specific to health institutions, individual reactions to violations, and changing perceptions of privacy. One of the questions was the features of privacy violation experienced by either patient or other family members. The findings of that part of the study have shown blurring of the borders for violation to privacy as a concept, admitting that approach justifiable, and frequent observation of voluntary disclosure against disrespect of privacy, and the features of privacy violation experienced by either patient or other family members.

Firstly, the effect of social and traditional media on the privacy of the patients and their relatives was evaluated under the sub-groups as privacy violation via social media, fake news spread via social media, and the appearance on social media. The privacy experiences related to healthcare facilities, and the personal information drawn either from hospitals or during filiation activities, respect to patient's privacy by the healthcare professionals were the issues among the second group of the findings. In following, different approaches of individuals to privacy violation were observed as not counting as privacy violation, unawareness about the leaker, voluntary disclosure, refrainment from disclosure, and reacting harshly. The last section of findings was consisted of the two subgroups for perception to privacy: the change in privacy perception and malevolent privacy violation.

1. The Impact of Social and Traditional Media on Privacy

When personal information was shared, its dissemination on social media, whether as true or false (fake) news, leads to its rapid and widespread learning by third parties, causing various social issues for patients and their families. On the other hand, situations arise where accurate information was given but without the consent of the individuals involved, resulting in privacy violations, especially when the information reached local or national media. There were also instances where individuals viewed these shares as opportunities for increased recognition or being frequently contacted with good wishes (without finding it strange that strangers were calling).

a. Violation of Patient Privacy Through Social Media

Information that concerns people and information that interests them are different. It is possible to claim the former while serving the latter. Yusof and colleagues suggested the scope of "basic rights such as acting on one's own will and respect for privacy and confidentiality" for this fine line. In connection with this, they proposed that to ethically justify the sharing of a COVID-19 patient's personal information, the benefit (protecting public safety against the disease) had to outweigh the harm (66).

Yılmaz, under the heading where he generalizes that "every communication is a privacy violation," explains the allure created by the combination of curiosity and privacy violation in interpersonal and media communications with the concept of news value for the media (67). In this context, Yusof and colleagues noted that journalists, bloggers, or anyone with access to social media considered the pandemic as an opportunity to share information about COVID-19 to attract more attention and increase their number of readers or viewers. They even highlighted the possibility that these individuals might manipulate news and stories or write them from scratch to capture the public's interest more effectively (66). Due to its prevalence during the pandemic, sharing patient news thoughtlessly on social media accounts became somewhat of a norm. While some might choose to stay away from social media to protect themselves, there was a possibility that they may remain unaware of the violation of their privacy in addition to genuinely protecting themselves.

> *I don't use social media, but there is a photo that was previously posted there. They mentioned my workplace, went and took a photo of my workplace, and combined it with my*

> *photo to share it with a message saying, "If you went there, see a doctor immediately and get tested."* **Interviewee 1**

> *No, I haven't experienced that. I don't use social media much for personal purposes anyway. I only use it for work purposes.* **Interviewee 45**

Since it is an infectious disease, there was a tendency to excuse these reports made without the approval of the individuals involved, with the thought that it is important for others to know so they could take precautionary measures, and not to perceive them as privacy violations.

> *I didn't mind. It's an illness; it can happen. For me, it's more important for it to be known so everyone can be careful. But my wife's brother shared on Facebook that his mother was in the intensive care unit. Everyone found out we were sick. I got angry with him not because he announced our illness but because it was unnecessary.* **Interviewee 35**

From the perspective of sharing information that might seem interesting to people, it could cause harm to the person whose privacy was violated, bringing no benefit to society or even a small group of people, and causing distress.

> *Every department has its own WhatsApp group now, and so did we. Inevitably, my friends learned I was hospitalized the next morning. They talked in that WhatsApp group as if I wasn't there, even though they knew I was. Since then, I've distanced myself from two people because, inevitably, you get hurt.* **Interviewee 29**

b. Spreading False News Through Social Media

One of the concepts that has become part of everyday language during the pandemic is "infodemic," derived from the combination of information and epidemic. It refers to the rapid spread of both accurate and inaccurate information. It was first used during the 2003 SARS outbreak and has resurfaced with the COVID-19 pandemic (68). The spread of unverified information is attributed to citizens disseminating false news and misinformation without thoughtful consideration (66). Misinformation (whether intentionally or unintentionally spread) is aimed at informing, whereas fake news involves a deliberate attempt to convince the audience with a fabricated story (69). Hao and Basu stated that the infodemic has exacerbated the pandemic by causing unnecessary alarm, creating uncertainty, and dividing society (70).

On a micro level, this scope could also relate to the experiences of patients within their close environment. According to interviewees, such impacts were distressing and difficult to manage. Patients, who felt so worn out that they wanted to cut off communication with others and struggle to respond to inquisitive calls, often learnt about false reports regarding their private lives later because they did not use social media. A doctor-patient interviewee recounted that another doctor from the hospital did not consider revealing the patient's real identity in an online comment on false/misleading news a privacy violation. Moreover, the reason for the private hospital's subsequent decision to withhold disease news from the media was not respect for the right to privacy. False news about severe illness and death negatively affected both the patient and their relatives, especially children.

> *I didn't have the chance to turn off my phone or say, “I don't want to see or hear any of you except my close relatives.” They didn't let me experience my illness because they didn't respect it. I learned later that there were even rumors about my separation from my spouse.* **Interviewee 1**

> *On the first day I was hospitalized, local internet news reported 'a doctor in a private hospital got COVID.' They wrote that I was an orthopedic specialist, and then the hospital's orthopedic specialist commented under the news, “It's not me, it's the hospital's general surgery specialist.” We had the news removed. The private hospital was more affected than I was, and they worked harder on it. Because if it was known that a doctor in the private hospital had COVID, patients would avoid going there. After me, seven more staff members got COVID, but they didn't announce any of them.* **Interviewee 10**

> *We have a WhatsApp group with very old friends. Someone wrote there, “X's – referring to me – condition is very bad, friends, pray for him. They have taken him to the ICU.” I followed these messages on WhatsApp.* **Interviewee 42**

> *Of course, children follow social media better than we do. The news of my death was posted there, and my daughter was shocked. This is outright terror...* **Interviewee 21**

c. Appearing in Traditional Media

The risk of COVID-19 patients being publicly blamed for initiating infections within certain communities increases, and sometimes patients subjected to such accusations openly react to defend themselves (66). Examples included news and statements about patients identified by numbers. In particular, the news about *Patient 26*, who was blamed for starting the second wave in Malaysia, became prominent when this individual exclaimed, “I am not the zero patient!” as a response to all the news about him (71). All types of media should avoid associating disease clusters with nation, ethnicity, religion, profession, etc., to minimize the negative impact on these individuals (66).

In the early stages of the pandemic, there were noticeable deficiencies in the attempts of patients, whose personal information was shared without their consent in ways that violated their privacy, to seek legal recourse against these violations.

> *I work in a government institution, and our names were published in newspapers. I was actually going to sue, but... They didn't even use our initials, but directly wrote our names. We were exposed, and later they removed the article. Our general manager said that whatever was necessary would be done.* **Interviewee 37**

Information about the disease being broadcast as news was less reacted to compared to the spread of fake news. Moreover, these inaccurate reports, by portraying the patient's condition as much worse than it actually was, could cause sadness and anxiety among those who knew the person. In some cases, being the subject of news served a function such as informing distant relatives about the illness, and this situation was observed to be evaluated with religious themes, as it ensured that many people receive prayers.

> *Actually, I think a national television channel reported that three people from one family had died due to COVID. I didn't watch it, and honestly, I didn't search for it on the internet either, but an hour and a half after my uncle passed away, someone called to offer condolences. We were keeping it private because my sister, mother, and father were in the hospital. We didn't want to inform them. But there are journalists inside hospitals, it seems, and news is constantly being reported.* **Interviewee 8**

> *After being mayor for five years, I became famous on all social media platforms. Now they say, "You're in the top three most famous for Corona in Turkey." I was on every channel, every possible channel. (Laughs) Someone had connected with everyone, don't misunderstand, this is definitely not an accusation. Everyone must know someone somewhere. This is how news is received. There were reports like "He's going into the intensive care unit, he's about to be intubated." They even said I died at one point. News comes out, but I wish the news were true.* **Interviewee 23**

> *Interviewee: We were also on X News Agency. Spouse: They filmed his discharge from the intensive care unit. There was another official there. He was also filming. His brother also filmed. There were one or two people there, but no one asked us anything. Interviewee: I'm just thinking about us getting better. (Laughter) Everyone prayed, whether I knew them or not. (Laughter)* **Interviewee 31**

2. Privacy Experiences Related to Health Institutions

The practice of storing patient records in electronic environments without access restrictions in many healthcare institutions might have led to the unauthorized access of patient information by hospital employees or individuals who entered these areas without permission during the early days of the pandemic. In the case of contagious diseases like COVID-19, contact tracing, known as filiation (finding the source of the disease), directed towards the close contacts of newly diagnosed patients was also included in this context.

a. Allegation of Information Obtained from the Hospital

It was common for healthcare workers to respect privacy in face-to-face encounters. Although it was rare for information to be directly leaked by healthcare workers, there could be breaches in the operation of the health system. Storing patient information in electronic environments could lead to certain security vulnerabilities. Access rights to patient files in hospital systems usually varied according to needs. Examples of privacy breaches in the early cases spread quickly among physicians as warnings, and measures were taken by defining access rights to patient information to specific users by the hospitals' IT units.

> *Especially, everything happened without our knowledge and without consent... It causes significant emotional distress to people already facing biological challenges. Even when I was just undergoing my first pneumonia treatment, before my COVID status was confirmed, information about us being COVID-positive began to circulate. Photos and the name of my spouse were shared openly. On social media, they claimed, "We got this information directly from the hospital." You reach a point where you can't stand it anymore.* **Interviewee 22**

b. Sharing Information through Contact Tracing

The process carried out by individuals assigned to contact tracing involved detailed interviews with the diagnosed patient to learn whom they had contact with during the infectious period of the disease, asking about the specifics of these contacts to assess the risk, and then making decisions regarding testing or isolation of the contacts based on the level of risk. These efforts, which might involve identifying a source patient who was not the diagnosed individual or ensuring treatment if transmission has already occurred, were aimed at controlling the outbreak. During periods of high patient numbers or in remote areas, individuals from professions other than healthcare workers, such as teachers or local leaders, have also been assigned to this task. Since the inherent security of information sharing between doctors and patients might not apply to these other professions, it was important to provide information on this matter. Additionally, if the doctor involved was not the one the patient chose and who has been overseeing their care, this could cause patient apprehension.

> *When I told the nurse who entered my room to provide information about an issue that I had been called by the Health Directorate and they wanted to reach my family, she said, "I don't know if you see this as a good or bad thing, but I did it; because if there is such a situation in your family, it will be beneficial to resolve it and take necessary precautions as soon as possible." I found her action logical and did not react, in fact, I appreciated her attitude.* **Interviewee 2**

> *I was very surprised that other doctors called me besides our own doctor at the health center. I might have responded negatively to one or two doctors because at that time there were warnings saying, "They might call you claiming to be your doctor." When the third*

> *one called, I gave them all the information, but to the previous ones, I said, "Why are you calling, why are you asking for my cell phone and my spouse's phone?" I was already very distressed.* **Interviewee 13**

Another scenario in contact tracing was when a doctor had fallen ill, and the patients they have recently examined come under the scrutiny of the filiation detectives. The change in roles lead to experiences within the wide range of possibilities in human relationships. A doctor, now experiencing the patient position, might react when their expectations of care and attention were not met. It was even observed that they might use an impolite tone towards patients they were attending to while they were sick (37).

> *They called the patients I had recently seen during filiation. My patients called me; some of them, without even saying "Get well soon," asked "Will we be affected?" I got angry. To those who started with "How are you, how are you doing, get well soon," I thanked them and explained that they need not worry.* **Interviewee 10**

When filiation teams could not reach the patient, they might try different methods to obtain the information they needed. This significantly breached the patient's privacy, and the patient might learn after their challenging health struggle that their family, workplace, and friends were all affected. The dilemma grew between the contribution of reducing transmission to controlling the outbreak and the difficulty in protecting the privacy of those included in the extensive measures.

> *They took my eighty-three-year-old grandmother. They quarantined my mother and father for fifteen days. They closed the place where I work for fifteen days. They put my friends from the village under house arrest for fifteen days. We are in a small place in the village. Inevitably, the fact that my illness was made known to them was very bad for me. They had to stay at home because of me. I caused harm to my workplace. I was very upset with myself.* **Interviewee 3**

c. Respect for Privacy

When a doctor respects their patient's privacy, it led to the patient trusting their doctor in all aspects, including other health-related matters. On the other hand, some patients experienced a level of confidentiality where even they were not given information, which suggested a confusion between protecting privacy and the patient's right to information. It was also observed that friends who had contact with the patient might obtain information out of concern and then spread the information about the illness to others.

> *I saw that the people around me, especially my doctor, were very careful about my privacy, and my doctor even set a boundary saying, "My patient must be comfortable; no information will be given on this matter." Thanks to my doctor, I felt very secure. The management also supported me a lot in this matter.* **Interviewee 4**

> *They don't give any information; for example, since we were not given any information, we told acquaintances and elders and had them call the doctor. They said it was forbidden, 'No information will be given.'* **Interviewee 43**

> *They spread this at my workplace. It wasn't announced by the hospital; friends told it. Later, everyone started calling us, "You have COVID, you have Corona." Everyone around us panicked. They kept calling, "What were the results of your tests? Are they negative?" "Yes, negative, negative," we said. But the news spread that we were COVID-positive.* **Interviewee 44**

3. Different Approaches to Privacy by Individuals

In addition to the aspects of the concept of privacy that were discussed, particularly in terms of public benefit, individual differences in approaches to this topic might be resulted more from the contextual relationship between the illness experienced and the disclosure of the illness to others without the individual's knowledge, rather than cultural determinants. Among the interviewee statements, there were various approaches such as not seeing the act as a privacy violation, not knowing the source that spread the information, voluntary disclosure, avoiding mentioning the illness, and reacting to privacy violations with anger. The most common among these was the approach of excusing the violation.

a. Not Seeing It as a Privacy Violation

It is common to encounter people who did not see the sharing of information about their illness with others without their consent as a privacy violation. Some interviewees did not find this behavior problematic, considering it natural or even necessary for the spread of information about their illness so that others could protect themselves from the disease or reach out with well wishes.

> *The illness gets heard about, of course. There's no problem in that regard. My relatives must have told everyone, and they all heard about it.* **Interviewee 7**

> *Our family is large, so everyone heard. This is a small place where everyone knows each other. Of course, here everyone tells everyone else. I was happy; may God keep our loved ones with us.* **Interviewee 9**

> *One friend told another, and that one told another, and so the news spread. Of course, many people called because of the news. Even after I recovered, people would call to say "Get well soon" when they heard I had COVID. But they found out, and I didn't think it was inappropriate or feel uncomfortable about why they learned about it.* **Interviewee 14**

> *No, everyone heard anyway. The manager wrote it in the group. Honestly, everyone in the building knew in the end. We were in quarantine; we went to the village. Everyone in the village also heard. Nothing happened, really...* **Interviewee 50**

b. Not Knowing the Source of the Information Spread

Personal information about patients could spread quickly both on social media and within the community. Some interviewees could only speculate about how the information was obtained or who shared it with others. Despite not knowing how the information about their illness spread, interviewees expressed a range of reactions: refusing to appear in the news, not being bothered by the situation as they consider the illness something that could happen to anyone and accepting calls from unknown people as normal.

> *Only once did X News Agency call and say, "We want to come and interview you." I said, "I don't want that." I would say they heard it from the hospital, or maybe from the community. A friend of a friend must have heard it. They could have checked Facebook, found out who my closest friend is. These things didn't bother me. This could happen to anyone.* **Interviewee 33**

> *When I was discharged from the hospital, everyone who knew me said, "Get well soon. Are you okay? We were very worried. If you need anything, let us know." Everyone had heard.*

> *Who heard it and how, honestly, I don't know either. There was nothing that bothered me.* **Interviewee 36**

c. Voluntary Disclosure

While there were COVID-19 patients who isolate themselves, others did not prioritize privacy. Notably, many interviewees voluntarily disclosed their illness. The reasons for this tendency to disclose their illness varied individually but often included seeking attention from loved ones, avoiding loneliness during isolation, coping with the negative effects of not being able to physically interact with others by maintaining social connections, seeking prayers for recovery according to their religious beliefs, and altruistically warning others to protect them. Particularly, those who adhered strictly to precautions from the beginning might feel more comfortable disclosing their illness, possibly due to a lack of guilt.

> *I don't have an attitude of reluctance because I announced it immediately. I even informed our working group. I told the managers, "Inform everyone." If we can catch it despite being so careful, others can too. At least I wanted it to be known in the institution where I work. Is it really the right attitude to hide it after contracting such an illness? People need to be careful.* **Interviewee 12**

> *I called and told people myself, so they could pray. After all, the only thing you can hold on to is prayer. I didn't feel uncomfortable about this; I don't think it's something to be ashamed of. I don't think the illness was due to my carelessness.* **Interviewee 13**

> *I don't think there's anything to hide; everything in my life has always been open. We're experiencing something different. It should be recorded in history, as you're doing, and examined from different perspectives.* **Interviewee 27**

> *During my discharge process, my friends kindly told me, "Brother, we will applaud and record a video when you leave here." I said, "Okay." I like such things. Of course, some may like it, some may not. They applauded, and I walked through them, saying "God bless you." Our news even appeared on national television.* **Interviewee 49**

d. Avoiding Disclosure

Individuals might choose to avoid disclosing their illness to prevent stigma, exclusion, and discrimination. This decision included determining where, when, and how to make the disclosure. However, it was observed that those who initially did not want their illness known often feel better after receiving social support once their condition is disclosed.

> *Only my spouse knew. I didn't inform anyone else because I would get emotional whenever someone called. In fact, an acquaintance called me for a work-related issue, and I told them, "Don't mention it to anyone." I didn't want people to find out, so I didn't share it.* **Interviewee 20**

> *I didn't want everyone to know, but my parents told most people; for example, I don't like some of my relatives, so I was a bit angry that they were informed. But then it wasn't an issue. They called every day and even supported me. That's why I felt happy afterward.* **Interviewee 25**

e. Reacting Sharply

Among the responses to the spread of accurate or false information about the illness, disregarding privacy and privacy violation, besides more common reactions such as silence, sadness, and trying to look on the bright side, there were also intense feelings of anger that were felt more intensely, as well as expressions containing harsh statements, and legal rights searches, later seen as an act of terror. Sennett's privacy despotism (72) gave the name to the phenomenon, a reverse reading of privacy violation, the subject and the object were encountered as having changed places in the narration of the victim who experienced the incident as an "act of terror":

> *I turned off my spouse's phone. After that, I turned my phone to silent mode. I did not communicate with anyone in any way unless absolutely necessary. But here's the thing, we have a family outside of us. We are not the only ones exposed to this terror. It's literally terrorism. Our children, our parents, are also exposed; our siblings are also exposed.* **Interviewee 22**

4. Situations Related to the Perception of Privacy

The fact that there was a debate over the concept of privacy seemed to be largely related to perception. However, when it came to a human right that was covered by the law, it was expected that the possibility of changing the approach to it according to perception will be limited. It was rare to find an example of recognizing the importance of privacy through one's own experience and drawing inferences from it to develop an attentive attitude in one's professional communications. There might be some realities that people working in the health sector perceive only when they were sick.

a. A Change in the Perspective of Privacy

Changing the perspective of privacy was not just about blurring the boundaries of the violation and rationalizing it on the grounds of pandemic conditions. It was observed that the attention to privacy of a COVID-19 patient working as a nurse in the healthcare process experienced with her colleagues affects her own perception of her profession.

> *My fellow nurses took great care of my privacy. We need to be very, very careful about privacy, because we all have a sense of shame.* **Interviewee 22**

b. Vicious Privacy Violations

The person who tried to carry the heavy burdens of the disease had to bear the psychological burden of violating his/her privacy with the spread of the information that he/she was sick.

> *There have been incredible phone calls because the Association of Dentists gave about my information to the whole of Turkey. Am I going to deal with Corona, my family, the people I've infected, curious people, or the people who really think about me and call me? I called the president of the association. I said, "Do you realize what you're doing?" He said, "Put your phone on silent." They see me as a rival. Frankly, they are a little jealous, and most of the people in the village are still propagandizing against me. I don't have many patients from the village anymore.* **Interviewer 40**

Failure to respect confidentiality and violation of one's right to privacy ultimately lead to stigmatization and exclusion.

> *People insisted on making it a matter of curiosity. They were just saying, "Is what I'm hearing true?" Also, people I didn't know were writing on Instagram. I was like, "Yes, that's right"; He didn't write anything else. There were people on my count who said, "Is it true that I heard, you have coronavirus?" In other words, he didn't say get well soon, he didn't say how are you, just messages of curiosity came a lot.* **Interviewer 40**

Discussing the findings on patient privacy

The starting point when discussing the concept of privacy is generally its status as a human right. Moreover, this right appears to be safeguarded both by societal norms and laws. While laws provide a more standardized approach to this issue, the nature and specificity of norms can vary due to cultural differences between societies, sometimes leading to differences in interpretation. As a result, situations can arise within the spectrum of privacy where respect and violations are at two extremes. One reason why the concept of privacy has prominently emerged in modern society could be attributed to the Enlightenment philosophy's focus on the free individual. With approaches centered around the individual, humans have moved away from the communal visibility of every moment of life because of collective agricultural production in traditional societies, towards differentiation and specialization, becoming individuals equipped with singular values and certain rights. While in some discussions, the term privacy is used synonymously with private life, the concept encompasses more than what this term implies. Essentially, privacy involves the act of an individual deciding, based on the thought that an individual walls off all their physical, mental, emotional, and experiential components, with them deciding only who, where, when, and how much to create an exception.

In legal language, it is seen that the realm of private life and the realm of confidentiality together constitute the scope of privacy. In his writing, Mehmet Yüksel defined privacy rights as the authority of individuals to decide on the extent of their participation in public life and this participation (73). Sennett's statement is noteworthy for its summary and comprehensive definition: "Public space was human creation; private space was human condition" (72). In discussing privacy, the concept of private space holds an important place. While public space includes all spaces shared with others for very different purposes and purposeless actions, private space corresponds to a small community close to the individual. In this context, in terms of privacy, the relationship between these two spaces emerges as the individual's experiences in the private space - without the individual's approval - are shared with others in the public space. For the individual expecting respect for their privacy, privacy can become established as a norm in society when other individuals accept the right to have similar expectations. This right has also been protected by laws in the modern world.

At the core of patient-physician consultations lies the assurance that confidentiality will be maintained. Following principles recognized as good medical practice, this involves taking a comprehensive medical history that seeks clues leading to a diagnosis and storing them in written records. Medical records contain a plethora of information about the patient and sometimes their family members, encompassing current and past physical conditions, illnesses, injuries, treatments, medications, mental health and psychological state (in detail regarding treatment), diet, medication use (legal or illegal), social life, habits, sexual orientation (open and confidential), hobbies, as well as demographic characteristics such as education, occupation, marital status, and family structure. A detailed medical history can provide numerous clues for narrowing down or highlighting potential diagnoses. When gathering this information, it is important to inform the patient about the rationale for medical use and provide assurances regarding the preservation of confidentiality.

Diagnostic results are also part of patient confidentiality. Recording these results will not only enable the physician to maintain control over the patient's condition during the monitoring process but will also serve as a source of documentation in legal matters. Furthermore, certain sensitive information may need to be stored separately and more securely. The careful preservation of fingerprints left by patients in healthcare institutions is crucial for respecting patient confidentiality. Privacy not only falls within the realm of ethical courtesy but also encompasses ensuring the suitability of clinical and research tools in the healthcare field.

While there may be differences in the laws of countries, the OECD defines personal data in a manner binding its member countries to protect cross-border privacy in its guidelines as “any data related to an identified or identifiable individual,” aiming to prevent violations of fundamental human rights, illegal data collection, storage of incorrect data, misuse of collected data, or unauthorized sharing (1980). The updated version of the guidelines in 2013 added risk management and global-scale applications (74). The Global Privacy Assembly (GPA), especially during the

COVID-19 pandemic, emphasizes the importance of not relaxing protection measures related to personal data and states its objectives as “finding the right balance between examining current privacy concerns, supporting innovations in combating the pandemic, and ensuring respect for individuals' personal data and right to information” (75). In Turkey, the Personal Data Protection Board (in Turkish known as KVKK), in its public announcement shared on its website, highlights the continued validity of Articles 5 and 6 of Law No. 6698 on the Protection of Personal Data during the pandemic period (76). The Turkish Medical Association defines privacy as a human right directly associated with many concepts such as private life, body, property, and sexuality, advocating not only the concealment of what needs to be hidden but also the preservation of individual autonomy within the scope of professional secrecy (77).

Privacy, a fundamental right for patients, is argued not to be extended to healthcare workers, especially during pandemics. Examples cited in Adhiyaman's letter to the editor illustrated that healthcare workers who temporarily left work due to COVID-19 suspicion or confirmed diagnosis could not keep this information hidden from their colleagues. In fact, if they took a break from work due to a health issue potentially linked to COVID-19, this information quickly became known to everyone, highlighting a breach of privacy where the necessity to respect privacy was not even considered, and the individual's experiences were openly and explicitly discussed at all levels (78).

Advancements in technology today have facilitated the rapid dissemination and increased reach of any information. Technology alone, no matter how advanced, could not achieve this. The swift and far-reaching journey of information shared in narrow scales such as private or interpersonal communications, but under specific conditions, only requires more than the will of technology. As emphasized by Yüksel, “The issue to be addressed is not technology itself, but the attitudes, perspectives, habits, and mindsets of individuals utilizing these technologies, public officials, and public institutions regarding human rights and freedoms” (73). The virus causing the pandemic, linked to a highly contagious infectious disease, made it somewhat understandable to society that information about who was affected could be shared through communication channels, social media platforms, and even visual and written press organs without much consideration. The rationale often cited was that if the disease was known, precautionary measures could be taken. While aiming to increase public awareness about the disease, individual privacy could be disregarded. Yusof and colleagues discussed two unethical types of information sharing on social media: first, sharing personal information of patients and their families with third parties, and second, sharing false news or misinformation. Proposed solutions included enhancing the society's skills in evaluating and verifying information validity and realizing that sharing ethical and valid information only was a moral responsibility for all parties involved in social media (66).

In a statement concerning patient privacy, the British Medical Association (BMA) emphasized the necessity for informed consent in all publications and records accessible to the public through media, including medical publications, without the requirement for patient recognition. Furthermore, the statement warned that patients who initially consented to publication and recording could not retract their consent for subsequent uses (79). The driving forces behind interpersonal communication or communication through media, curiosity and interest in privacy, were noted, with the suggestion that curiosity in this context included a breach of privacy (67). Gavison also suggested that if an individual became a subject of curiosity, conscious, intentional, or accidental, privacy might be violated. Privacy was defined as the disappearance of at least one of the independent components mentioned: privacy, anonymity, and loneliness (64). On March 31, 2020, the United Nations published a warning on its website regarding infodemic (80). The World Health Organization describes “an excessive amount of information containing inaccuracies, thereby making it difficult for the public to receive honest information and reliable advice when needed” (81). One year after the onset of the pandemic, the World Health Organization had to make a global call. This call highlighted the difficulty of combating infodemic (emphasizing the importance of information hygiene) alongside new technologies that allow for the widespread dissemination of information and evidence about this new disease, while also pointing out that social media environments carried falsehoods and distortions that were more visible and difficult to cope with than in other fields, such as disease (82). The spread of false news was important in terms of violating the privacy of COVID-19 patients, which would make it difficult for patients and their families to have social life. The findings of the study also demonstrated the negative effects of psychological distress.

Starting with the determination that unauthorized individuals attempted numerous entries into their system to access the record of a famous person during the time they were hospitalized, Cushman points out the seriousness of such a privacy problem (83). It is likely that well-known individuals will appear in traditional media. Sometimes they may also think that this sharing is news. It is known that there are health correspondents in hospitals. However, especially the importance of pretending to be a close person of the patient, the ethics of journalism, the level of awareness of health workers about the protection of patient privacy are important. Along with the COVID-19 pandemic, those who were interested in news that would attract readers, especially the disease news of well-known people in society, were on the trail.

The preservation of patient privacy is fundamentally an issue of medical ethics. Privacy, which can be defined as promising or having a responsibility to protect information privacy, is considered one of the most important ethical issues in patient care. In the patient-doctor relationship, the importance of this issue in the healthcare system is significant because patients provide personal and sensitive information to their doctors that they do not want others to know (84). It is widely recognized that patients have the right to the protection of their medical privacy. This right includes the obligation for healthcare providers to keep personal and identifiable medical information learned from patients confidential and private, without disclosing it to third parties without the informed consent of the patient. According to legal and medical ethical principles, sharing this information is not considered a violation of privacy if it is requested by court order or if a specific person or community is at significant risk. Furthermore, in accordance with medical ethics, care must be taken to maintain privacy when sharing information about patients among healthcare professionals. Neitzke described the practice at Hannover University Hospital, where during consultations with other doctors, information that could reveal the patient's identity, such as their name, is discussed anonymously unless the patient has given informed consent (84). It is important to draw attention to ensuring that health professionals respect the content and consent of the subject when sharing information and preventing unauthorized leaks of information from healthcare institutions. A physician from the United States who began storing patient information many years ago emphasized the problems that could arise in an article at the time. In this article, Cushman argues that the request to restrict access to health records should be understandable, based on these records containing the most intimate and private information about an individual (83). It is interesting to observe that individuals have different approaches when their privacy rights are violated and their right to privacy is not respected. This range includes responses ranging from ordinary acceptance to harsh reactions. Goffman noted that if individuals accepted themselves as they were and respected themselves, they might not need to hide information potentially discredit them, considering voluntary disclosure as a sign of ethical career stages. In a sense, an individual marked with a secret stigma, when they disclose this information, may partially disclose their disclosure policy, thereby starting adaptive actions to reach a state of peace (37). They will consider themselves deserving of achieving peace by avoiding the tension that would occur from hiding their illness rather than hearing about it from others. The opposite approach is in the form of hiding. When a person enters Goffman's definition of susceptibility to stigmatization, they have to manage information about their situation (keep it under control) rather than manage the tensions during social relationships when they know or anticipate that their current situation is likely to be stigmatized in society. In short, by choosing between saying-not saying, revealing-not revealing, they establish a strategy (37).

Shekhawat and colleagues discussed the topic of special changes to patient privacy and confidentiality during COVID-19. In their letter to the editor, they evaluated privacy breaches implemented by the government in India, such as stamping the backs of patients' hands, recording the identity of household members under quarantine, and sending selfies periodically to demonstrate compliance with quarantine, all justified under the pretext of preventing the spread of the disease (25). The National Health Service in the United Kingdom also appears to have suspended patient confidentiality specifically in relation to COVID-19. In the relevant article, it was noted that general practitioners announced to their patients through their own websites, “In order for you to receive the healthcare you need during this difficult time, we may urgently need to share your personal information, including your medical records, with medical and non-medical staff of organizations who are authorized to use your records for combating the COVID-19 pandemic.” Additionally, after listing the scope of their actions, including their use in research and the benefits they might provide, they specified that information and medical data would only be shared when necessary for individuals' and public healthcare (85). It is striking that none of these statements include any mention of obtaining consent from patients.

Members of society who do not consider such possibilities may be deceived into believing the accuracy of information spread through social media or word of mouth (66). The authors explicitly declared as morally unacceptable situations where such information was knowingly and intentionally shared to deceive others. Bauman asserts that human relationships are ethical to the extent that they are conducted based on the well-being and welfare of the other person, emphasizing that this moral responsibility should not prioritize self-interest, should be entirely separate from selfishness, and should be fulfilled unconditionally (86). According to Bauman, when the relationship between people takes the form of competition, parties act with the desire to exclude their actual or potential rivals from using resources they control, hope to control, or fantasize about controlling. This is because it is assumed that the goods competed for are scarce, not enough to satisfy everyone, and convincing some competitors to settle for less than the amount they want is necessary.

Failure to respect privacy can lead to various individual problems, especially discrimination. Misbelief in spreading infectious diseases can lead to individuals being stigmatized and excluded. Regarding the social concepts that the pandemic necessitates rethinking, the blurred line between respecting privacy and violating privacy observed in previous experiences can be discussed. In a sense, privacy violations create an environment for stigmatization, exclusion, discrimination, and social inequality. From this perspective, experiences of leaking health information of COVID-19 patients from healthcare institutions, as observed in the study, demonstrated that this ethical tradition has been suspended for various reasons.

The COVID-19 pandemic is not only the first major epidemic in human history but also unlikely to be the last. Yet, suggestions based on previous experiences regarding social issues have not been implemented by policymakers or medical professionals. The fact that recent epidemics did not reach pandemic proportions may have led to a perception that they only affected people in a particular geographic region, failing to trigger global-scale measures. Despite numerous scientific articles identifying social problems caused by previous outbreaks, preventable similar issues continued to persist during the COVID-19 pandemic. Moreover, the compounding effect of uncertainty specific to this new outbreak has observed an increase in both frequency and diversity of these issues. Social scientific issues investigated in the context of COVID-19 often included anxiety, privacy concerns, stigma, isolation, economic impacts, and the nature of family relationships, presented as revisions or reports based on previous articles (13, 15, 35, 61, 87). There is no other study in the literature that investigates these issues, especially through qualitative research techniques, by conducting in-depth interviews.

Findings from the research indicate a transformation of privacy in sociological terms, specifically in the context of COVID-19. Due to the rapid spread of the disease, patient information was shared without the consent of the individual under the pretext of “public interest”. As a result, patients might come to accept such breaches of privacy as natural occurrences. Additionally, it was frequently observed that many patients voluntarily disclose their illness to their surroundings or to broader communities via social media. Moreover, justifications such as “the benefit outweighs the harm” or “considering the benefit of the general public” were not easily contested. Adorno's prediction is articulated as follows: “Acting according to reason will become a self-preservation stripped of ego, a perversion called the state of the world, where the strong win” (88). The functions of privacy on human life, freedom, autonomy, selfhood, and supporting human relationships were defined as advancing the existence of a free society (Gavison, 1980). Recognizing the dual aspects of these functions opens the way for understanding the expectations of privacy for an individual who expects respect for their privacy.

Generally, it is noted that the criterion for observing ethical principles in sharing any information about another person lies in distinguishing between a topic of public interest and one that is interesting to the public (66). Conditions for sharing information about a patient without their consent by healthcare workers should be reconsidered in cases of legal obligation or anonymization requirements. For individuals in the public, many of these conditions were said to be out of play, as it was proposed that those making such disclosures should be healthcare workers if it was a necessity for the public good. Yusof and colleagues suggested developing the ability to evaluate the value of information acquired by everyone, learning to distinguish useless information before pressing message directing and sending buttons (66). Deepening nuances on privacy, filtering every step through a finely perforated privacy breach filter, might be recommended.

In conclusion, this research indicates a transformation of sociological concepts in the context of COVID-19. If new outbreaks emerge, measures to prevent patients from experiencing privacy breaches leading to societal and psychological adverse effects are crucial for future experiences.

Epilogue

This study reveals the social impacts of patients diagnosed with COVID-19 who underwent hospital isolation and continued quarantine at home after discharge, discusses the experiences related to respect or violation for their privacy, as well as stigma and exclusion linked to their illness. Through a multidimensional assessment, experiences related to each component of these social issues were observed from various domains. Among these, particularly prominent experiences will be highlighted in this section, by emphasizing the significance of evaluating them with proposed solutions or providing a perspective for the future.

The COVID-19 pandemic was not only the first major epidemic in human history but also unlikely to be the last. Yet, suggestions based on previous experiences regarding social issues have not been implemented by policymakers or medical professionals. The fact that recent epidemics did not reach pandemic dimension may have led to a perception that they only affected people in a particular geographic region, failing to trigger global-scale measures. Despite numerous scientific articles identifying social problems caused by previous outbreaks, preventable similar issues continue to persist during the COVID-19 pandemic. Moreover, the compounding effect of uncertainty specific to this new outbreak has observed an increase in both frequency and diversity of these issues.

While social issues in previous pandemics were predominantly studied on samples consisting mostly of healthcare workers and patients under isolation conditions, with fewer samples from the general population, these studies were often quantitative in design. Despite containing sufficient scientific findings to draw attention to the issue, they have not sufficiently propelled societal and political preparedness at the points they indicate. This situation has been clearly highlighted in articles published specifically on COVID-19, mostly comprising reviews or perspective articles. Social scientific issues investigated in the context of COVID-19 often included anxiety, privacy concerns, stigma, isolation, economic impacts, and the nature of family relationships, presented as revisions or reports based on previous articles mostly used qualitative research techniques, while they didn’t investigate all these issues comprehensively.

The findings of recent study reveal a transformation in sociological concepts specific to COVID-19, particularly concerning privacy. With the rapid spread of the disease, sharing patient information under the pretext of “public interest” has become normalized. This normalization occurred as patients increasingly accepted such privacy violations as natural, often voluntarily disclosing their illness on social media. The justification of “the greater good outweighing individual harm” became a prevailing argument. Adorno's foresight aptly captures this shift: “Acting rationally will become abstract self-protection devoid of ego and self, turning into a state where evil triumphs in what is called the world order.” Gavison defined privacy's functions as supporting freedom, autonomy, selfhood, and enhancing human relationships, essential for a free society. Understanding these dual facets helps in recognizing others' privacy expectations, grounded in mutual respect for privacy.

Ethically, the distinction between public concern and public interest is crucial. The British Medical Association defines public concern as related to “the general welfare and rights of the public.” They provide guidelines for healthcare workers on sharing patient information without consent, emphasizing legal obligations and anonymization. However, these conditions often do not apply to the general public, suggesting that healthcare workers should handle such disclosures when necessary for public benefit. Yusof and colleagues recommended that individuals develop the ability to evaluate the information they receive, discerning non-functional information before sharing. By doing so, we can contribute to the collective effort against COVID-19, achieving more through collective action. It seems advisable to scrutinize each step through a fine-grained privacy violation filter by delving into nuances. Socrates' Three Filters Test, proposed millennia ago (469-399 BCE), can serve as a tool in making this distinction. According to this test, before speaking about a person, one should ensure that what is to be said is completely true (the truth filter), good (the goodness filter), and useful to the person learning it (the usefulness test). The interviewees' statements revealed how failing to pass this test can put the individuals concerned in difficult situations.

Another important issue is that isolation and quarantine are practices that significantly contribute to preventing the spread of infectious diseases. If new outbreaks occur, it is foreseeable that isolating patients and quarantining those at risk of developing the disease will continue as effective infection control measures. However, it is crucial to reassess and determine the conditions, understand their effects, and take precautions against potentially negative outcomes for future experiences. The researcher's subjective experience, influenced by patient interviews conducted within the study, led to the integration of support measures into their professional practice during the second peak period when the number of patients was rising again. These measures included providing explanations to alleviate anxiety, ensuring that patients were minimally affected by the isolation conditions. The importance of this contribution lies in learning about the patients' experiences in detail and examining their narratives from sociological perspectives. Recognizing humans as biopsychosocial beings is essential for everyone in the medical field to adopt, as it guarantees societal well-being, which is the complete health of the community.

A notable observation specific to COVID-19 is the 'self-exclusion' behavior among patients. This widespread behavior indicates an altruistic attitude in the context of an infectious disease, as reflected in the interviewees' statements. A general observation was that when voluntary disclosure occurs, both exclusion and stigmatization were experienced less frequent. Nevertheless, further studies are needed to determine whether self-exclusion behavior has such an effect.

From the beginning of the COVID-19 pandemic, major health organizations rapidly published frequently updated guidelines and general information documents to assist patients biologically, even though many uncertainties remained by the end of the pandemic's first year. On the other hand, the rapid spread of misinformation alongside accurate information necessitated swift preventive measures. The Turkish Psychiatric Association's information document on infodemic (March 22, 2020) consists of the Turkish translation of the WHO's guide (February 24, 2020). Additionally, the accumulation of knowledge on stigmatization through qualitative research on infectious diseases like Tuberculosis, HIV/AIDS, appears to have influenced the inclusion of this issue in guidelines. It is important to prepare similar and updated guidelines and strive for their widespread dissemination.

Two more parts of the study were not included in this book: the effects on relationships with family members, friends, relatives, and neighbors, and the economic effects on COVID-19 patients. They may be the subject of another book. There is no specific reason to exclude these two important parts. The translations into English were already made with the aim of a scientific publication, so it would be possible to combine them into a book format. However, a brief comment on the findings related to economic influences may give readers of this book an idea: “Ulrich Beck highlights the holistic approach to equal impact through the global risks posed by environmental pollution, even though not the danger of epidemics, and argues that risks, like wealth, are also objects of distribution (89). Although the fact that all people are at risk of contracting COVID-19 might create the impression that the disease eliminates inequality, the privileged classes' ease of access to healthcare, their ability to avoid the income loss that comes from being unable to work during isolation and quarantine periods, and generally being unaffected by interruptions in work, reproduce inequality. In light of the findings of the research, it can be observed that those with high and low incomes are equal within their own classes but unequal between classes, leading to the characterization of the COVID-19 pandemic as an 'equalizer in inequality.'"

It is important to consider limitations when evaluating the research findings. Although care was taken to create a sample spread across the country, reaching only those patients who could be interviewed online (including those who received help from their relatives) required patients to have internet infrastructure and either themselves or at least one relative to be familiar with technology. On the other hand, there is evidence of diversity when looking at data such as occupation and monthly income levels. While it would have been advantageous to include participants in face-to-face interviews without the risk of disease transmission, such a study could be possible by means of the main advantages as including participants in the research for long online interviews without the risk of disease transmission and avoiding travel to make interviews all around the country in pandemic conditions.

Adding the participants with socio-economic groups that cannot be reached by online interviews may provide further valuable results when the pandemic conditions that caused the mentioned limitations disappear. However, it is invaluable to inscroll the experiences when all are fresh in memories and their effects are still timely. A notable observation among most interviewees is their effort to insistently convey the time, often down to the day and sometimes the hour, in their narratives of past (illness period) experiences. This could be an unconscious reaction to the intense sense of chaos they felt while living through it. The knowledge that time is abstract and impersonal in human communities and that this is socially organized suggests that the seemingly individual preference might have a "social time" background. Additionally, the approach of emphatically mentioning the name of a family member, relative, or even someone encountered briefly, despite the researcher not knowing them, might show a desire to point to witnesses of their experiences.

It is a significant responsibility for individuals who witness historical events, especially scientists, to document these occurrences with an objective and social perspective. Recording individuals' experiences using scientific research methods is an effective way to ensure preparedness for similar future events. As a result of this study, we – not only decision-makers and stakeholder, but also physicians, who must consider the social impacts on their patients – equip future generations with the knowledge and tools necessary to navigate and overcome the challenges that lie ahead, ultimately fostering a resilient and informed society by learning from the past and preserving these insights.

References

1. World Health Organization (WHO) (2020). WHO Director-General's opening remarks at the media briefing on COVID-19. Available at https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---11-march-2020. (29.07.2024).

2. Anadolu Ajansı (AA). (11 March 2020). Sağlık Bakanı Koca Türkiye'de ilk koronavirüs vakasının görüldüğünü açıkladı. [The head of Ministry of Health, Fahrettin Koca, announced that the first case of COVID-19 was diagnosed]. Available at https://www.aa.com.tr/tr/koronavirus/saglik-bakani-koca-turkiyede-ilk-koronavirus-vakasinin-goruldugunu-acikladi/1761466. (29.07.2024).

3. Zhu, N., Zhang, D., Wang, W., Li, X., Yang, B., Song, J. & Tan, W. (2020). A Novel Coronavirus from patients with pneumonia in China, 2019. *New England Journal of Medicine, 382*, 727-733. DOI: 10.1056/NEJMoa2001017.

4. Li, Q., Guan, X., Wu, P., Wang, X., Zhou, L., Tong, Y. & Feng, Z. (2020). Early transmission dynamics in Wuhan, China, of Novel Coronavirus-infected pneumonia. *New England Journal of Medicine, 382*, 1199-1207. DOI: 10.1056/NEJMoa2001316.

5. Wu, Z. & McGoogan, J. M. (2020). Characteristics of and important lessons from the Coronavirus Disease 2019 (COVID-19) outbreak in China: Summary of a report of 72 314 cases from the Chinese Center for Disease Control and Prevention. *JAMA,* 323(13).1239-1242. DOI: 10.1001/jama.2020.2648.

6. Asmundson, G. J. G. & Taylor, S. (2020). Coronaphobia: fear and the 2019-nCoV outbreak. *Journal of Anxiety Disorders, 70*:102196. DOI: 10.1016/j.janxdis.2020.102196.

7. Sotgiu, G., Carta, G., Suelzu, L., Carta, D. & Migliori. G. B. (2020). How to demystify COVID-19 and reduce social stigma. The International Journal of Tuberculosis and Lung *Disease, 24*(6), 640-642. DOI: 10.5588/ijtld.20.0233.

8. Foucault, M. (1995). *Discipline and Punish: The Birth of the Prison*. Vintage Books.

9. Parsons, T. (2002). *The Social System* (2nd ed.). Routledge.

10. Centers for Disease Control and Prevention (CDC). (2017). Quarantine and Isolation. Available at https://www.cdc.gov/quarantine/index.html. (29.07.2024).

11. World Health Organization (WHO) (2020). Coronavirus disease (COVID-19) advice for the public. Available at https://www.who.int/emergencies/diseases/novel-coronavirus-2019/advice-for-public, (last updated at 3 March 2021). (29.07.2024).
12. EKMUD (Turkish Infectious Disease and Clinical Microbiology Association) (2020). COVID-19 Guidelines of Turkish Ministry of Health. Available at https://www.ekmud.org.tr/haber/453-t-c-saglik-bakanligi-covid-19-rehberleri-arsivi. (29.07.2024).
13. Fan, P. E. M., Aloweni, F., Lim, S. H., Ang, S. Y., Perera, K., Quek, A. H. & Ayre, T. C. (2020). Needs and concerns of patients in isolation care units-learnings from COVID-19: a reflection. *World Journal of Clinical Cases, 8*(10), 1763-1766 https://dx.doi.org/10.12998/wjcc.v8.i10.1763.
14. Newton, J. T., Constable, D. & Senior, V. (2001). Patients' perceptions of methicillin-resistant staphylococcus aureus and source isolation: a qualitative analysis of source-isolated patients. *Journal of Hospital Infection, 48*, 275-280. DOI: 10.1053/jhin.2001.1019.
15. Brooks, S. K., Webster, R. K., Smith, L. E., Woodland, L., Wessely, S., Greenburg, N. & Rubin, G. J. (2020). The psychological impact of quarantine and how to reduce it: rapid review of the evidence. *The Lancet, 395*, 912-920. https://doi.org/10.1016/S0140-6736(20)30460-8.
16. Maslow, A. H. (1943). A Theory of human motivation. *Psychological Review, 50*(4), 370-396. https://doi.org/10.1037/h0054346.
17. Bourdieu, P. (1986). The Forms of Capital. In: J. G. Richardson (Ed.), *Handbook of Theory and Research for the Sociology of Education*, pp. 241-258, Greenwood. Available at https://revise-it.co.uk/wp-content/uploads/2020/05/bourdieu_forms_of_capital-1.pdf. (29.07.2024).
18. Hyun, M., Lee, J. Y., Kwon, Y., Kim, J. Y., Park, J. S. Park, S., Ryoo, N. & Kim H. A. (2020). COVID-19: Comparing the applicability of shared room and single room occupancy. *Transboundary Emergency Diseases*, *00*;1-7. https://doi.org/10.1111/tbed.13853.

19. Abad, C., Fearday, A. & Safdar, N. (2010). Adverse effects of isolation in hospitalised patients: a systematic review, *Journal of Hospital Infections, 76*, 97-102 DOI: 10.1016/j.jhin.2010.04.027.
20. Kirkland, K. B. & Weinstein, J. M. (1999). Adverse effects of contact isolation. *Lancet, 2*, 354(9185), 1177-1178. DOI: 10.1016/S0140-6736(99)04196-3.
21. Saint, S., Higgins, L. A., Nallamothu, B. K. & Chenoweth, C. (2003). Do physicians examine patients in contact isolation less frequently? A brief report. *American Journal of Infection Control, 31*(6), 354-356. DOI: 10.1016/s0196-6553(02)48250-8.
22. Moore, K. A. & March, E. (2020). Socially connected during COVID-19: online social connections mediate the relationship between loneliness and positive coping strategies, Preprint (Version 1) available at Research Square, 1-14. https://doi.org/10.21203/rs.3.rs-35835/v1.
23. Kaniasty, K. (2012). Predicting social psychological well-being following trauma: the role of postdisaster social support. *Psychological Trauma: Theory, Research, Practice, and Policy, 4*(1), 22-33. https://doi.org/10.1037/a0021412.
24. Beck, U. (2001). *La société du risque, sur la voie d'une autre modernité*. Alto Aubier.
25. Shekhawat, R. S., Meshram, V. P., Kanchan, T. & Misra, S. (2020). Privacy and patient confidentiality in times of Covid-19. *Medico-Legal Journal, 88*(4), 229-230. DOI: 10.1177/0025817220935908.
26. Mechanic, D. (1986). Illness Behaviour: An Overview. In: McHugh S. & Vallis T. M. (eds) *Illness Behavior*. Springer, 101-109. https://doi.org/10.1007/978-1-4684-5257-0_6.
27. Foucault, M. (2003). *The Birth of the Clinic. An Archaeology of Medical Perception*. Routledge
28. Conrad, P. (1992). Medicalization and social control. *Annual Review of Sociology, 18*(1), 209-232.
29. Zola, I. K. (1972). Medicine as an institution of social control. *The Sociological Review, 20*(4), 487-504. DOI: 10.1111/j.1467-954X.1972.tb00220.x.
30. Illich, I. (2001). *Limits to Medicine: Medical Nemesis: The Expropriation of Health*. Marion Boyars Publishers Ltd.

31. Banerjee, D. & Nair, V. S. (2020). Handling the COVID-19 Pandemic: proposing a community based toolkit for psycho-social management and preparedness. *Asian Journal of Psychiatry, 51*, 102152. https://doi.org/10.1016/j.ajp.2020.102152.
32. He, Z. (2020). What further should be done to control COVID-19 outbreaks in addition to cases isolation and contact tracing measures?, *BMC Medicine, 18*, 80. https://doi.org/10.1186/s12916-020-01551-8.
33. Backer, J. A., Klinkenberg, D. & Wallinga, J. (2020). Incubation period of 2019 Novel Coronavirus (2019-Ncov) infections among travellers from Wuhan, China, 20-28 January 2020. *Euro Surveillance, 25*(5):2000062. https://doi.org/10.2807/1560-7917.ES.2020.25.5.2000062.
34. Lee, S., Kim, T., Lee, E., Lee, C., Kim, H., Rhee, H., Park, S. Y., Son, H-J, Yu, S, Park J. W., Choo, E. J., Park S., Loeb, M. & Kim, T. H. (2020). Clinical course and molecular viral shedding among asymptomatic and symptomatic patients with SARS-CoV-2 infection in a Community Treatment Center in the Republic of Korea. *JAMA Internal Medicine, 180*(11), 1447-1452. https://doi.org/10.1001/jamainternmed.2020.3862.
35. Bruns, D. P., Kraguljac, N. V. & Bruns, T. R. (2020). COVID-19: facts, cultural considerations, and risk of stigmatization. *Journal of Transcultural Nursing, 31*(4): 326–332. DOI: 10.1177/1043659620917724.
36. Turner, B. S. (2007). *Medical Power and Social Knowledge* (2nd ed.). SAGE Publications.
37. Goffman, E. (1963). *Stigma: Notes on The Management of Spoiled Identity*. Englewood Cliffs, New Jersey: Prentice Hall.
38. Canguilhem, G. (2013). *Le normal et le pathologique*. Presses Universitaires de France, Paris.
39. Shaban, R. Z., Nahidi, S., Sotomayor-Castillo, C., Li, C., Gilroy, N., O'sullivan, M. V. N & Bag, S. (2020). SARS-Cov-2 infection and COVID-19: the lived experience and perceptions of patients in isolation and care in an Australian healthcare setting. *American Journal of Infection Control, 48*(12), 1445-1450. https://doi.org/10.1016/j.ajic.2020.08.032.

40. Patel, A., Patel, S., Fulzele, P., Mohod, S. & Chhabra, K. G. (2020). Quarantine an effective mode for control of the spread of COVID19? *A Review, Journal of Family Medicine and Primary Care, 9*(8), 3867-3871. https://doi.org/10.4103/jfmpc.jfmpc_785_20.
41. Weber, M. (1969). *Le savant et le politique*. Plon.
42. Budhwani, H. & Sun, R. (2020). Creating COVID-19 stigma by referencing the Novel Coronavirus as the "Chinese virus" on Twitter: quantitative analysis of social media data. *Journal of Medical Internet Research, 22*(5): e19301.
43. Link, B. & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27*, 363-385. https://www.jstor.org/stable/2678626.
44. Person, B., Sy, F., Holton, K., Govert, B., Liang, A., Garza, B. & Zauderer, L. (2004). Fear and stigma: the epidemic within the SARS outbreak. *Emerging Infectious Diseases, 10*(2), 358–363.
45. Heijnders, M. & Van Der Meij, S. (2006). The fight against stigma: an overview of stigma-reduction strategies and interventions. *Psychology, Health & Medicine, 11*(3): 353–363.
46. World Health Organization (WHO) (2021). Turkey. Available at https://covid19.who.int/region/euro/country/tr. (29.07.2024).
47. Eren-Bana, P. (2020). Evaluation of the social implication perception of healthcare employees in the COVID-19 outbreak process. *Press Academia Procedia (PAP), 11*: 115–119.
48. Ergur, A. (2020). *Ateş ve İhanet: Sağlık Çalışanlarının COVID Kliniğinde Deneyimleri [The Experinces of the Healtcare Workers in the COVID-19 Clinics: Fire and Betrayal]*, Raskolnikov Kitap.
49. Bagcchi, S. (2020). Stigma during the COVID-19 pandemic. *The Lancet. Infectious Diseases, 20*(7): 782.
50. Singh, R. & Subedi, M. (2020). COVID-19 and stigma: social discrimination towards frontline healthcare providers and COVID-19 recovered patients in Nepal. *Asian Journal of Psychiatry, 53*:102222.
51. Park, S. & Park, K. S. (2014). Family stigma: a concept analysis. *Asian Nursing Research, 8*(3), 165–171.

52. Major, B. & O’brien, L. T. (2005). The social psychology of stigma. *Annual Review of Psychology, 56*(1): 393–421.

53. Courtwright, A. & Turner, A. N. (2010). Tuberculosis and stigmatization: pathways and interventions. *Public Health Reports (Washington, D.C.:1974), 125*(Suppl 4): 34–42.

54. Courtwright, A. M. (2009). Justice, stigma, and the new epidemiology of health disparities. *Bioethics, 23*(2): 90–96.

55. Parker, R. & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: a Conceptual framework and implications for action. Social Science and Medicine, 57(1): 13–24.

56. Becker, H. S. (1985). *Outsiders, Études de sociologie de la déviance*, Métailié.

57. Kane, J. C., Elafros, M. A., Murray, S. M., Mitchell, E. M. H., Augustinavicius, J. L., Causevic, S. & Baral, S. D. (2019). A scoping review of health-related stigma outcomes for high-burden diseases in low and middle-income countries. *BMC Medicine, 17*: 17.

58. Barrett, R. & Brown, P. J. (2008). Stigma in the time of influenza: social and institutional responses to pandemic emergencies. *Journal of Infectious Diseases, 15*(197); Suppl 1: S34–S37. DOI: 10.1086/524986.

59. Taylor, S., Landry, C. A., Rachor, G. S., Paluszek, M. M. & Asmundson, G. J. G. (2020). Fear and avoidance of healthcare workers: an important, under-recognized form of stigmatization during the COVID-19 pandemic. *Journal of Anxiety and Disorders, 75*:102289.

60. Hawryluck, L., Gold, W. L., Robinson, S., Pogorski, S., Galea, S. & Styra, R. (2004). SARS control and psychological effects of quarantine, Toronto, Canada. *Emerging Infectious Diseases, 10*(7): 1206–1212.

61. Collins, R. (2020). Social distancing as a critical test of the micro-sociology of solidarity. *American Journal of Cultural Sociology, 8*, 477-497. https://link.springer.com/article/10.1057/s41290-020-00120-z.

62. Chang, S. H. & Cataldo, J. K. (2014). A systematic review of global cultural variations in knowledge, attitudes and health responses to tuberculosis stigma. *International Journal of Tuberculosis and Lung Diseases, 18*(2): 168–173.

63. Cremers, A. L., De Laat, M. M., Kapata, N., Gerrets, R., Klipstein-Grobusch, K. & Grobusch, M. P. (2015). Assessing the consequences of stigma for tuberculosis patients in Urban Zambia. *PLoS ONE, 10*(3): e0119861.
64. Gavison, R. (1980). Privacy and the limits of law. *The Yale Law Journal, 89*(3), 421-471. DOI: 10.2307/795891.
65. Durkheim, É. (2009). *Le suicide*. Petite Bibliothèque Payot.
66. Yusof, A. N. M., Muuti, M. Z., Ariffin, L. A. & Tan, M. K. M. (2020). Sharing information on COVID-19: The ethical challenges in the Malaysian setting. *Asian Bioethics Review, 12*: 349-361. https://doi.org/10.1007/s41649-020-00132-4.
67. Yılmaz, S. (2011). Every communication is an invasion of privacy, and every invasion of privacy has a news value [Her iletişim bir mahremiyet ihlalidir ve her mahremiyet ihlalinin bir haber değeri vardır]. In: Hüseyin Köse (ed), Media Intimate-The Phenomenon of Privacy in Media and Fragments of a Transparent Life [Medya Mahrem-Medyada Mahremiyet Olgusu ve Transparan Bir Yaşamdan Parçalar]. İstanbul, Ayrıntı Yayınları, 129-148.
68. Wikidaily (2021). Infodemic. Available at https://m.wikidaily.org/wiki/Infodemic. (29.07.2024).
69. Molina, M. D., Sundar, S. S., Le, T. & Lee, D. (2019). 'Fake News' is not simply false information: a concept explication and taxonomy of online content. *American Behavioral Scientist, 65* (2), 180-212. https://doi.org/10.1177/0002764219878224.
70. Hao, K. & Basu, T. (12 February 2020). The Coronavirus is the first true social-media 'Infodemic'. MIT Technology Review, Available at https://www.technologyreview.com/2020/02/12/844851/the-coronavirus-is-the-first-true-social-media-infodemic/. (29.07.2024).
71. Sukumaran, T. (6 March 2020). 'I'm not patient zero': Malaysia's 26th Coronavirus patient speaks up about new Covid-19 cluster. South China Morning Post, Available at https://www.scmp.com/week-asia/health-environment/article/3073991/im-not-patient-zero-malaysias-26th-coronavirus-patient. (29.07.2024).

72. Sennett, R. (2019). *The Fall of the Public Man* [Kamusal İnsanın Çöküşü] (S. Durak, A. Yılmaz, translator, 6. press). İstanbul, Ayrıntı Yayınları.

73. Yüksel, M. (2003). The right to privacy and its socio-historical development [Mahremiyet hakkı ve sosyo-tarihsel gelişimi]. *Ankara Üniversitesi SBF Dergisi, 58*(1), 181-213. DOI: 10.1501/SBFder_0000001619.

74. OECD. (2024). Recommendation of the council concerning guidelines governing the protection of privacy and transborder flows of personal data. Available at https://legalinstruments.oecd.org/en/instruments/OECD-LEGAL-0188. (29.07.2024).

75. Global Privacy Assembly (GPA). (2020). Sources and library. Available at https://globalprivacyassembly.org/covid19/covid19-resources/. (29.07.2024).

76. Kişisel Verilerin Korunması Kurulu (KVKK). (2020). On protection of personal data during the fight against COVID-19. Available at https://www.kvkk.gov.tr/Icerik/6731/PUBLIC-ANNOUNCEMENT. (29.07.2024).

77. Türk Tabipleri Birliği (TTB). (2020). Declaration on the protection of the right to privacy [Mahremiyet hakkının korunmasına ilişkin bildirge]. In: Türk Tabipleri Birliği etik bildirgeleri. Available at https://www.ttb.org.tr/kutuphane/etikbildirgeler2020.pdf. (29.07.2024).

78. Adhiyaman, V. (2020). COVID-19: Lack of confidentiality affects healthcare staff too. *BMJ, 369*, m2293. http://dx.doi.org/10.1136/bmj.m2293.

79. British Medical Association (BMA). (8 September 2020). Confidentiality and disclosure of health information tool kit. London, British Medical Association. Available at https://www.bma.org.uk/advice-and-support/ethics/confidentiality-and-health-records/confidentiality-and-health-records-toolkit. (29.07.2024).

80. United Nations (UN). (31 March 2020). UN tackles ‘Infodemic’ of misinformation and cybercrime in COVID-19 crisis. Available at https://www.un.org/en/un-coronavirus-communications-team/un-tackling-%E2%80%98infodemic%E2%80%99-misinformation-and-cybercrime-covid-19. (29.07.2024).

81. World Health Organization (WHO). (15 April 2020). Coronavirus Disease 2019 (COVID-19) situation report-86. Available at https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200415-sitrep-86-covid-19.pdf. (29.07.2024).

82. World Health Organization (WHO) (11 December 2020). Call for action: Managing the infodemic. Available at https://www.who.int/news/item/11-12-2020-call-for-action-managing-the-infodemic. (29.07.2024).

83. Cushman, R. (1996). Information and medical ethics: protecting patient privacy. *IEEE Technology and Society Magazine,15*(3), 32-39. DOI: 10.1109/44.536299.

84. Neitzke, G. (2007). Confidentiality, secrecy, and privacy in ethics consultation. *HEC Forum, 19*, 293-302. https://doi.org/10.1007/s10730-007-9049-y.

85. Dyer, C. (2020). COVID-19: Rules on sharing confidential patient information are relaxed in England. *BMJ, 369*, m1378. DOI: 10.1136/bmj.m1378.

86. Bauman, Z. (2016). *Thinking Sociologically* [Sosyolojik Düşünmek]. (A. Yılmaz, translator, 13. press). İstanbul, Ayrıntı.

87. Cinel, E. (2020). Global macroeconomic effects of Covid-19 and expectations [Covid-19'un küresel makroekonomik etkileri ve beklentiler]. *Politik Ekonomik Kuram, 4*(1), 124-140.

88. Adorno, T. W. (2012). *Problems of Moral Philosophy* [Ahlak Felsefesinin Sorunları] (T. Birkan, translator.). İstanbul, Metis Yayınları.

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