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Long-term Post COVID-19 Health and Psychosocial Effects and Coping Resources Among Severe and Critical COVID-19 Survivors in Central and Eastern Europe: Protocol for a Cross-National Qualitative Study

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Abstract

Background: The countries in Central and Eastern Europe have been among the most heavily affected by the COVID-19 pandemic in Europe, which has been associated with death rates and excess mortality among the highest in the world. Among the long-term effects of COVID-19 is the post COVID-19 condition – a prolonged form of the disease characterized by a variety of physical and psychological symptoms, which can last for more than 2 years and is associated with the severity of acute COVID-19 as a main risk factor. A positive long-term COVID-19 outcome is post-traumatic growth, occurred in response to the highly challenging life circumstances and traumatic experiences during the pandemic. COVID-19 survivors' personal, social and other resources play an important role in coping with acute disease and post-acute negative sequalae and contribute to the development of post-traumatic growth.

Objective: The aim of the study is to qualitatively explore the experiences of severe or critical COVID-19 adult survivors throughout the acute and post-acute period in the region of Central and Eastern Europe in terms of: negative long-term post-COVID effects (physical and psychological symptoms); positive long-term post-COVID effects (post-traumatic growth); the role of survivors' personal, social and other coping resources; the role of the local sociocultural context and local epidemic-related situations in the participating countries.

Methods: In-depth semi-structured interviews with adult severe and critical COVID-19 survivors are conducted in the period post hospital discharge. Participants are enrolled based on self-reported severe or critical acute COVID-19 disease, defined in accordance with clinical classifications of COVID-19 severity as COVID-19 hospitalization or ICU treatment. The questionnaire follows the experiences of survivors across the trajectory of disease, from pre-infection COVID-19 attitudes to first symptoms, hospitalization, recovery, and post-discharge adjustment. Interviews are conducted in person, through videoconferencing or telephone, audio-taped and transcribed verbatim. Qualitative data are analyzed through thematic analysis in two stages. In stage 1, analysis of each national dataset in the national language is done. In stage 2, the national analyses will be collated. Based on the cross-national analysis, conclusions about the Central and Eastern European region will be drawn.

Results: As of January 2024, data collection is completed in Bulgaria (N=33), Slovakia (N=30), and Romania (N=30) and is ongoing in Croatia and Poland. Analyses of the national datasets are currently underway. Papers based on the national results have been submitted. Cross-national analyses have started in 2024.

Conclusions: The study provides insight into COVID-19 survivors' experiences in the under-researched region of Central and Eastern Europe, enabling better understanding of their needs for care and support and allowing for the development of socioculturally appropriate tailored approaches to providing support for coping with the post COVID-19 condition and associated difficulties and to implementing interventions to facilitate post-traumatic growth.

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Protocol

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Abstract

Background: The countries in Central and Eastern Europe have been among the most heavily affected by the COVID-19 pandemic in Europe, which has been associated with death rates and excess mortality among the highest in the world. Among the long-term effects of COVID-19 is the post COVID-19 condition – a prolonged form of the disease characterized by a variety of physical and psychological symptoms, which can last for more than 2 years and is associated with the severity of acute COVID-19 as a main risk factor. A positive long-term COVID-19 outcome is post-traumatic growth, occurred in response to the highly challenging life circumstances and traumatic experiences during the pandemic. COVID-19 survivors' personal,

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Conclusions: The study provides insight into COVID-19 survivors' experiences in the under-researched region of Central and Eastern Europe, enabling better understanding of their needs for care and support and allowing for the development of socioculturally appropriate tailored approaches to providing support for coping with the post COVID-19 condition and associated difficulties and to implementing interventions to facilitate post-traumatic growth.

Keywords: COVID-19 survivors; severe COVID-19; COVID-19 hospitalization; long-term COVID-19 effects; post COVID-19 condition; post-traumatic growth; coping resources; qualitative; cross-national; Central and Eastern Europe

Introduction

The COVID-19 Pandemic in the Region of Central and Eastern Europe

The global COVID-19 pandemic has become a major health crisis across the world. Europe has been the epicenter of the pandemic several times in the period 2020-2022 and has reported the largest cumulative number of COVID-19 cases among WHO regions [1]. The countries in Central and Eastern Europe have been among the most heavily affected in Europe. Overall, the

pandemic period has been characterized by relatively high infection rates, extremely high death rates and very low vaccination rates. As of January 14, 2024, cumulative total data show 34 381 reported COVID-19 cases per 100 000 population in Slovakia, 32 274 cases in Croatia, 19 077 cases in Bulgaria, and 18 186 cases in Romania. Cumulative total reported COVID-19 deaths per 100 000 population are 556 in Bulgaria (second in the world), 460 in Croatia (seventh in the world), 389 in Slovakia (twelfth in the world), and 355 in Romania (fifteenth in the world) [1]. The COVID-19 pandemic has led to excess mortality in Europe. The most affected during the second wave (autumn-winter 2020) have been the countries in Central and Eastern Europe (Czechia, Slovakia, Bulgaria, and Poland). In the spring of 2021, the highest mortality rates have been recorded in Bulgaria (period average 168 % and period maximum 202 %), Romania (period average 163 % and period maximum 230 %), and Slovakia (period average 153 % and period maximum 193 %) [2]. Peaks in COVID-19 hospitalizations as high as 20 529 patients in Romania on October 26, 2021, and 10 355 patients in Bulgaria on April 11, 2021, have been registered [3]. The number of COVID-19 patients in Intensive Care Units per million has reached 117,81 in Bulgaria (April 18, 2021), 112,17 in Slovakia (February 27, 2021) and 96,75 in Romania (November 7, 2021) [4]. Bulgaria, Romania, Slovakia, and Croatia have the lowest percentage of total population vaccinated with at least one dose of a COVID-19 vaccine in the European Union – 30% in Bulgaria, 42% in Romania, 52% in Slovakia, and 57% in Croatia [1].

Post COVID-19 Condition

As the COVID-19 pandemic has progressed, a prolonged form of the disease, known as post COVID-19 condition (or long COVID, post-COVID-19 syndrome, post-acute sequelae of SARS-CoV-2 infection-PASC) has been identified. The condition is characterized by long-term symptoms and complications that continue or develop after acute COVID-19. The World Health Organization defines the post COVID-19 condition as occurring usually 3 months from the onset of COVID-19 with symptoms and that last for at least 2 months and cannot be explained by an alternative diagnosis. Symptoms may be new onset, following initial recovery from an acute COVID-19 episode, or persist from the initial illness and generally have an impact on everyday functioning. Symptoms may also fluctuate or relapse over time [5]. Clinical guidelines in the United Kingdom and the United States define the prolonged form of COVID-19 as symptoms ongoing for 4 weeks or more [6,7].

A variety of long-term patient-reported symptoms have been identified in adult COVID-19 survivors, with over 200 different symptoms reported across 10 organ systems [8]. Commonly reported symptoms include fatigue, shortness of breath, brain fog (concentration problems, cognitive disfunction), headache, dizziness, weakness, post-exertional malaise, depression, hair loss, loss or change in taste and/or smell, gastrointestinal symptoms, cough, nausea and vomiting, sweating, palpitations, intermittent fever, chest pain/discomfort, joint pain, body aches, sleep disturbance, memory loss, hearing loss or tinnitus, anxiety, post-traumatic stress, reduced pulmonary capacity, skin rash, and allergic reactions [8-12]. More severe post COVID-19 condition has been associated with worse well-being and quality of life, worse perceived overall health [13], difficulties to perform daily tasks [8,10,11,13], reduced ability to work

[8,14] and social and family life impairment [14]. Post COVID-19 symptoms (most commonly fatigue) and lower quality of life have been found in both hospitalized and non-hospitalized COVID-19 survivors at follow-up 2 years after symptom onset, though in significantly lower proportions compared to the 6-month follow-up [15,16].

Risk Factors for Post COVID-19 Condition: Acute COVID-19 Severity

Severe COVID-19 disease and hospitalization have been considered as key risk factors for post COVID-19 condition across studies [10, 17-19]. Classifications of COVID-19 severity have been provided by clinical guidelines for the treatment of COVID-19 of the World Health Organization [20,21] and the National Institutes of Health, USA [22]. According to these classifications, non-severe COVID-19 includes asymptomatic or presymptomatic infection [22], mild illness (symptoms of COVID-19, but without evidence of viral pneumonia or hypoxia [20,21], and moderate illness (defined as clinical signs of pneumonia but no signs of severe pneumonia, including SpO2≥90% on room air [20,21] or evidence of lower respiratory disease and an oxygen saturation measured by pulse oximetry (SpO2)≥94% on room air at sea level [22]). Severe COVID-19 is defined by clinical signs of pneumonia (fever, cough, dyspnea) plus one of the following: oxygen saturation <90% on room air; severe pneumonia; signs of severe respiratory distress [21] or by SpO2<94% on room air at sea level, a ratio of arterial partial pressure of oxygen to fraction of inspired oxygen (PaO2/FiO2) <300 mm Hg, a respiratory rate >30 breaths/min, or lung infiltrates >50% [22]. Severe COVID-19 requires hospitalization and oxygen therapy. Critical COVID-19 is defined by acute respiratory distress syndrome (ARDS), sepsis, septic shock, or other conditions that would normally require the provision of life-sustaining therapies such as mechanical ventilation (invasive or non-invasive) or vasopressor therapy [21] or respiratory failure, septic shock, and/or multiple organ dysfunction [22]. Critical patients are treated in the intensive care unit (ICU).

Any person infected with SARS-CoV-2 can experience long-term post-acute COVID-19 effects, but the proportions are significantly higher among patients admitted to hospital with severe and critical COVID-19 disease. Prevalences of post COVID-19 condition have been estimated based on recruitment setting: community setting, hospital setting, or ICU setting [10,17]. A systematic review and meta-analysis estimated the prevalence of any post COVID-19 condition symptom at 50,6% (moderate certainty) among cohorts recruited in the community setting; 66,5% (moderate certainty) among cohorts recruited in the hospital setting; and 73,8% (low certainty) among cohorts recruited in the ICU setting [10]. A systematic review found that studies including more hospitalized participants or more patients in ICU tended to report higher prevalence estimates. The prevalence range in studies with 10% hospitalized participants was 0% to 67%, and in studies in which all participants were hospitalized the prevalence range was 5% to 93%. Studies in which 10% or more of the sample were admitted to ICU had prevalence estimate of 48.8% compared with 34.9% in studies with <5% of their samples admitted to ICU [17]. Among hospitalized patients, those who have been more severely ill during their hospital stay have had increased risk of pulmonary diffusion abnormality,

fatigue or muscle weakness, and anxiety or depression [18]. In hospitalized COVID-19 survivors, 2 years after symptom onset persisting symptoms have been related to decreased quality of life, lower exercise capacity, abnormal mental health, and increased use of health care after discharge. Survivors' physical health and health-related quality of life have still been poorer than those of control population [15].

Other risk factors for post COVID-19 condition are older age [12,13,17], female gender [12-15, 18,19], pre-existing chronic diseases (diabetes, hypertension, cardiovascular disease, respiratory disease, liver disease, kidney disease, and immunological disorder or allergy) [14,17,19], obesity [13,14,17], and non-vaccination status prior to infection [19].

Post-traumatic Growth and Coping Resources

Besides the negative long-term COVID-19 effects, a positive psychological outcome has occurred in response to the highly challenging life circumstances and traumatic experiences during the pandemic – post-traumatic growth [23]. The pandemic itself and the severe COVID-19 disease experience have significantly challenged the adaptive resources of individuals and their way of understanding the world and their place in it. "Life-changing" psychological shifts in thinking and relating to the world and the self have arisen, contributing to a deeply meaningful personal process of change in the areas of appreciation of life; relating to others; personal strength; new possibilities; and spiritual, existential, or philosophical change [23].

Aspects of post-traumatic growth in relation to the experience of the COVID-19 pandemic have been identified in the general population [24] and in persons infected with SARS-CoV-2 with various levels of disease severity and place of treatment [24-29], including severely or critically ill hospitalized COVID-19 survivors [26,27,30,31]. Higher levels of post-traumatic growth have been associated with higher severity of COVID-19 acute disease [26]. COVID-19-related post-traumatic growth has been found to coexist with negative psychological trauma-related outcomes such as anxiety, depression [26,30] and post-traumatic stress disorder [24-27, 30].

Coping resources are personal (e.g., optimism, psychological control or mastery, self-esteem), social (e.g., social support) or other resources (e.g., financial freedom) available to individuals for managing stress and coping with adversity, which interact with coping processes [32,33]. COVID-19 survivors' psychosocial resources play an important role in coping with both the acute disease and the post-acute negative sequalae. In a qualitative study of female COVID-19 survivors with persistent symptoms survivors have relied on individual (cognitive, emotional, and spiritual resources), social (social support from family, friends, co-workers, and online support groups) and health systems resources (guidance and treatment by counselors and medical professionals). Insufficient financial resources have been identified as a main challenge in the process of coping with long COVID [34].

Coping resources have an important role in the ability to cope with trauma and bring about positive change and have been found to be associated with post-traumatic growth. Personal resources associated with higher levels of COVID-19 induced post-traumatic growth include

optimism, self-compassion, self-transcendence, religiosity/spirituality, purpose in life, agreeableness, self-efficacy, sense of coherence [24], self-esteem [24,27], and resilience [24,25]. Social support has been proved to be a significant protective factor for the development of post-traumatic growth among the general population and COVID-19 survivors [24-29, 31], with family and friends being the most important source of social support [24, 29]. Financial safety has been negatively associated with post-traumatic growth [28].

Objectives

The aim of the study is to qualitatively explore the experiences of severe or critical COVID-19 adult survivors throughout the acute and post-acute period in four Central and Eastern European countries: Bulgaria, Slovakia, Croatia, and Romania (Poland has been associated to the study at a later stage). The study aims to examine patients' experiences in terms of 1) negative long-term post-COVID effects, such as physical and mental health symptoms, cognitive symptoms, post-traumatic stress, diminished functional ability, difficulties in social functioning, etc.; 2) positive long-term post-COVID effects, such as post-traumatic growth; 3) the role of survivors' coping resources, including personal (e.g., self-efficacy, resilience, hope, optimism), social (e.g., social support) and other (e.g., financial) coping resources; 4) the role of the local sociocultural context and the local epidemic-related situations in the participating countries.

Methods

Overview

This is a cross-national qualitative study, collecting data in five countries in the region of Central and Eastern Europe. The research methodology and study documentation have been developed in English and then translated into the national languages of the participating countries: Bulgarian, Slovak, Croatian, Romanian, and Polish. The method for qualitative data collection is in-depth semi-structured interviews, conducted post hospital discharge. The first four conducted interviews in each country serve as a pilot study for testing the study instrument and procedures. Based on the pilot study, revisions of the methodology have been made.

Participants

Participants in the study are adult (≥18 years) severe or critical COVID-19 survivors residing in one of the participating countries. Severe and critical COVID-19 disease is defined in accordance with WHO and NIH clinical guidelines and their clinical classifications of COVID-19 severity [20-22] with using the clinical judgement of the patient's condition as requiring hospitalization (severe COVID-19 disease) or ICU care (critical COVID-19 disease) according to

WHO guidance as the main criterion. Participants have been enrolled based on self-reported severe or critical COVID-19 disease. The following inclusion criteria have been applied: the participant has tested positive for SARS-CoV-2, the participant has had evidence of pneumonia, the participant has been hospitalized (for severe COVID-19), the participant has been hospitalized and admitted to ICU (for critical COVID-19). Severe COVID-19 survivors who were members of the family of a participant have been excluded.

The sample will be balanced by gender. The study tries to cover all adult life stages, ranging from emerging adulthood to late adulthood, while considering that the risk for severe acute COVID-19 disease and long-term post-COVID effects increases with age. After the considerable difficulties in recruiting study participants encountered during the pilot stage, it has been decided that the preliminary planned quotas based on age group, gender, and length of the period post hospital discharge cannot be achieved and that participating countries will try to balance the sample by these criteria as far as possible. Although having a chronic illness is not a criterion for inclusion in the study, a significant proportion of the sample is expected to have chronic conditions given that they are a risk factor for severe acute COVID-19 disease and long-term post-COVID-19 effects.

Semi-structured Questionnaire

Instruments include a specifically designed for the study semi-structured questionnaire (Interview Guide) and a demographic questionnaire. They have been developed in English and then translated to the national languages of the countries participating in the study.

The topics in the semi-structured questionnaire follow the experiences of survivors across the trajectory of disease, from pre-infection COVID-19 attitudes to first symptoms, hospitalization, recovery, and post-discharge adjustment: 1) patients' and their social circle's thoughts and feelings about the coronavirus disease and the management of the pandemic in their country prior to infection, including vaccination attitudes (if relevant); 2) patients' experiences during infection and disease course leading to hospitalization, including symptoms, existing chronic diseases, difficulties with access to testing, treatment, and hospitalization, infection of other family members, social support; 3) patients' experiences during hospitalization related to treatment, need of ICU care, relationships with medical personnel and with fellow patients, support by family and friends, satisfaction with stay in the hospital; 4) patients' experiences in the period after hospital discharge, including hospital discharge and meeting with family, persisting and new symptoms (physical, psychological, cognitive), seeking medical and psychological help for symptoms, seeking support from other COVID-19 survivors, ability to do usual activities as before COVID-19, going back to work/study, family and social life in the post-COVID period, social support, learning from experience and post-traumatic growth, personal coping resources, (changed) attitudes towards vaccination.

The demographic questionnaire collects data on gender, age, country, city of residence, ethnicity, marital status, having children, educational level, profession/occupation, length of

hospitalization, ICU treatment, length of post-discharge period, and chronic diseases.

Recruitment and Data Collection

The study employs a wide range of recruitment strategies, including invitations for participation in the study to individuals known by members of the research teams or referred to them through their social contacts, advertisements through research institutions' online pages, profiles and contact lists, advertisements in social media, approaching hospitals, rehabilitation services or individual healthcare professionals, referrals by study participants (snowball technique). The study attempts to include participants from different places of residence in the respective countries.

Considerable difficulties in recruitment of study participants have been encountered in all participating countries. The research teams have attributed them to the timing of data collection in the end of the pandemic (few people have been hospitalized with severe COVID-19 in this period) and high level of post COVID-19 trauma among potential participants and people asked for referrals. Most recruitment strategies have had low efficiency. This has led to extension of the period of data collection, which is still ongoing in Croatia and Poland.

The interviews are conducted by the members of the national research teams in person, through videoconferencing or telephone, depending on survivors' preferences and place of residence. An audio recording of the conversation is made after receiving permission from the participant. In the case of videoconferencing, only the audio recording of the meeting is used.

Ethical Considerations

Ethics Approval

Ethics approval for the study has been obtained from the Ethical Committee of the Institute for Population and Human Studies – Bulgarian Academy of Sciences, Approval No. RD-2-140/15.08.2022: "Health and Psychosocial Long-term Effects and Coping Resources in Severe or Critical COVID-19 Survivors: A Qualitative Study".

Informed Consent

Participants give their informed consent about their voluntary participation in the study. They are provided with the opportunity to withdraw their consent and terminate their participation at any time. An information sheet is part of the ethical documentation along with the informed consent form. It provides information about the study and explains the procedure, the voluntary participation, the right to withdraw from the study, anonymity and confidentiality of participant information, potential benefits and risks associated with study participation, and

the use of collected data only for scientific purposes.

Privacy and Confidentiality

Collected qualitative data are anonymized, with all potentially identifying information removed. Demographic information and qualitative data are analyzed in aggregate form only.

Compensation Details

No compensation is provided for research participants.

Data Processing and Analysis

The audio-taped interviews are transcribed verbatim using the automated transcription package of the NVivo software for qualitative data analysis which supports transcription in the national languages of the partners. The transcriptions are then checked by the researchers for accuracy and are corrected where needed. Demographic information and participant identifying data are organized in separate files and data are anonymized.

Data are analyzed through thematic analysis [35], defined as a method for systematically identifying, organizing, and offering insight into patterns of meaning anchored by a shared idea or concept (themes) across a dataset, revealing collective or shared meanings and experiences [36]. Meaning and meaning-making is context-bound, positioned, and situated. The analytic process includes searching for meanings and patterns in the data, generating codes, grouping codes into themes, and producing a thematic map – a complete conceptualization of the patterns in the data and the connections between them [35]. The six-phase process includes the phases 1) familiarizing with the data; 2) generating initial codes; 3) generating initial themes; 4) reviewing potential themes; 5) defining and naming themes; 6) producing the report [35-37]. Recently, Braun and Clarke [37,38] have labeled their approach “reflexive thematic analysis” to highlight that it is an active and generative process of immersion, thoughtfulness, and reflection, with researcher subjectivity being at the heart of the approach and understood as a resource. Analysis is assisted by NVivo software for qualitative data analysis.

Data analysis is conducted in two stages. In stage 1, thematic analysis of each national dataset in the national language is done and a national thematic map for each country’s data is produced. In stage 2, the national thematic maps will be translated in English and the national analyses will be collated. The cross-national analysis will reveal the common features and will highlight cross-national differences and underlying epidemic-related and sociocultural factors. The national results of the five countries will be integrated and an international thematic map will be produced. The process will involve discussions of data and results between the national

teams. Based on the cross-national analysis, conclusions about the Central and Eastern European region will be drawn.

Results

Funding

The project “Health and Psychosocial Long-term Effects and Coping Resources in Severe or Critical COVID-19 Survivors: A Qualitative Study” was funded by the Alliance of International Science Organizations (Project No. ANSO-CR-PP-2021-10) in October 2021, with a project implementation period January 1, 2022 – December 31, 2024, and participating countries Bulgaria, Slovakia, Croatia, and Romania.

Recruitment and Data Collection

Recruitment of participants and qualitative data collection (pilot study) started at the end of August 2022 for the main participating countries. Poland joined the study as an associate partner at a later stage (in the end of November 2022) and started recruiting participants and collecting data in January 2023.

As of January 2024, data collection is completed in Bulgaria (N=33), Slovakia (N=30), and Romania (N=30). Data collection is ongoing in Croatia and Poland and is expected to be completed in March 2024. Transcription is completed in Romania and ongoing in Bulgaria, Slovakia, Croatia, and Poland.

Data Analysis and Expected Results

Analyses of the national datasets are currently underway. Papers based on the national results have been submitted by Slovakia, Romania, and Croatia, and Bulgaria. Cross-national analyses have started in 2024. The results will be submitted for publication in 2024.

Discussion

To our knowledge, this is the first study to qualitatively examine and cross-nationally compare the experiences of severe and critical COVID-19 survivors throughout the course of the disease, with a focus on the post-acute period. Moreover, the study provides insight into survivors’ experiences in the region of Central and Eastern Europe which is generally insufficiently explored. This region has been hit hard during the pandemic, which has been associated with death rates and excess mortality among the highest in the world.

The study has been initiated amid the unprecedented global challenge to the health and wellbeing of human societies – the COVID-19 pandemic, to address this most urgent global need and the necessity for in-depth scientific knowledge of the disease, its treatment, and the struggles of healthcare systems and of (severe) COVID-19 patients and their families and friends. The study will advance scientific knowledge on the acute and prolonged forms and symptoms of the coronavirus disease, the subjective experiences and needs of patients, the mobilized coping resources during the fight with severe COVID-19, the emergence of positive psychological outcomes such as post-traumatic growth, the possibilities for psychosocial support through the recovery process. A part of this scientific knowledge is focused on the Central and Eastern European region with its specific sociocultural context, attitudes, and local epidemic-related situations that shape the experiences and impact the health outcomes of COVID-19 survivors.

Overall, the findings will be helpful in evaluating the overall impact of the pandemic and in informing future pandemic preparedness. The findings have important implications for improving the health outcomes of adult COVID-19 survivors. They will inform both healthcare practice in hospitals and rehabilitation services and informal caregiving and provision of psychological support to COVID-19 survivors. Knowing survivors' experiences enables better understanding of their needs for care and support and will allow for the development of socioculturally appropriate tailored approaches to providing health and psychosocial support for coping with the post COVID-19 condition and associated difficulties in different life domains, and to implementing interventions to facilitate post-traumatic growth.

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Conflicts of Interest

None declared.

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