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## Chapter

# The Advantages of an Integrative Approach in the Primary Healthcare of Post-COVID-19 and ME/CFS Patients

Diana Araja, Angelika Krumina, Uldis Berkis, Zaiga Nora-Krukle and Modra Murovska

### Abstract

The coronavirus disease caused by the SARS-CoV-2 virus (COVID-19) pandemic has changed not only global epidemiological and economic developments but also the lives of every individual, with particular severity for patients. The number of acute illness cases grew rapidly, significantly increasing the workload of hospitals, and simultaneously, new chronic diseases emerged, such as persistent post-COVID-19 syndrome (PPCS), with unclear etiology, symptoms, and complexity—similar to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Accordingly, the burden of chronic diseases poses new long-term challenges for primary healthcare and requires new approaches to patient care. This chapter provides insight into the integrative approach to healthcare and focuses on potentially new solutions by implementing an integrative attitude to the treatment of post-COVID-19 and ME/CFS patients in primary healthcare. Integrative health coaching contributes the holistic approach to patients' overall health and resilience through cognitive practice and patient active engagement. The findings of this chapter can enrich the personcentered approach and healthcare system strengthening through holistic measures and systems thinking.

**Keywords:** persistent post-COVID-19 syndrome (PPCS), myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS), integrative approach, coaching, patient-reported outcomes (PROs)

## 1. Introduction

The coronavirus disease caused by the SARS-CoV-2 virus (COVID-19) pandemic induced overload in acute healthcare and significantly increased the burden of chronic diseases. One of the new manifestations of chronic diseases is the post-COVID-19 disorder, for which a common definition has not yet been established, but which creates the preconditions for expanding the prevalence of related diseases. The results of an online survey of 3762 participants with confirmed (diagnostic/antibody positive; 1020) or suspected (diagnostic/antibody negative or untested; 2742) COVID-19, performed in 56 countries, from September 6, 2020 to November 25, 2020, demonstrated that 1700 respondents (45.2%) required a reduced work schedule compared to pre-illness, and an additional 839 (22.3%) were not working at the time of survey due to illness. After 6 months of the post-COVID conditions, the most frequent symptoms were fatigue, post-exertional malaise, and cognitive dysfunction. Cognitive dysfunction or memory issues were common across all age groups (~88%) [1]. Already in July 2020, Dr. Anthony Fauci, the Director of the National Institute for Allergy and Infectious Diseases (US Department of Health and Human Services), assumed that patients post-COVID-19 can develop "a post-viral syndrome that's very strikingly similar to myalgic encephalomyelitis/chronic fatigue syndrome" [2].

The authors, in one of the previous studies on the COVID-19 pandemic consistencies in healthcare [3], revealed that since October 2020, several articles have reported myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) as a potentially post-COVID-19-associated disease [4-11]. The literature reviews on the potential causal interaction between post-COVID-19 and ME/CFS also appeared in the following period [12–19]. The reviews' results highlighted problems associated with the definitions and diagnostic criteria for ME/CFS and post-COVID-19 disorder. There were various manifestations of the interaction between post-COVID-19 and ME/CFS, from the similarity of the symptoms to the assumption that it is the same disease [3]. Over time, the COVID-19 long-haulers reported an overall reduction of most symptoms including unrefreshing sleep and post-exertional malaise, but an intensification of neurocognitive symptoms. When compared to ME/CFS, the COVID-19 sample was initially more symptomatic for the immune and orthostatic domains but over time, the long-haulers evidenced significantly less severe symptoms than those with ME/CFS, except in the orthostatic domain [20]. However, almost all publications indicated the need for further research into the similarities and differences between post-COVID-19 and ME/CFS to determine the nature of these conditions and define risk factors, prevalence, and possible interventions [3].

Concerning the definitions, ME/CFS commonly is defined as a poorly understood, serious, complex, multisystem disorder, characterized by symptoms lasting at least 6 months, with severe incapacitating fatigue not alleviated by rest, and other symptoms—many autonomic or cognitive in nature—including profound fatigue, cognitive dysfunction, sleep disturbances, muscle pain, and post-exertional malaise, which lead to substantial reductions in the functional activity and quality of life [21]. The common definition of post-COVID-19 disorder has not yet been established, but the results of some studies suggest, for instance, that it is composed of heterogeneous sequelae that often affect multiple organ systems, with significant impacts on morbidity, mortality, and quality of life [1]. Regarding the defining post-COVID-19 symptoms, based on the relapsing/remitting nature of post-COVID-19 symptoms, the following integrative classification was proposed by researchers: potentially infection-related symptoms (up to 4–5 weeks), acute post-COVID-19 symptoms (from week 5 to week 12), long post-COVID-19 symptoms (from week 12 to week 24), and persistent post-COVID-19 symptoms (lasting more than 24 weeks) [22]. Therefore, in the context of the time reference, ME/CFS is most closely associated with persistent post-COVID symptoms.

Persistent post-COVID symptoms were considered in light of a new "syndrome," as the British Medical Association defines a syndrome "as a set of medical signs and symptoms which are correlated with each other and associated with a particular disease" [22]. Accordingly, the term "Persistent Post-COVID-19 Syndrome (PPCS)"

was introduced in practice, as a pathologic entity, which involves persistent physical, medical, and cognitive sequelae following COVID-19, including persistent immunosuppression as well as pulmonary, cardiac, and vascular fibrosis [23]. Consequently, some authors note that the preliminary findings raise concern regarding a possible future ME/CFS-like pandemic in SARS-CoV-2 survivors [24].

The prevalence of ME/CFS in population varies from 0.19% to 7,6% [21]. Based on the earlier studies on other infections, researchers suggested that 10% of COVID-19 survivors could develop ME/CFS [2]. Accordingly, it is estimated that the US ME/CFS prevalence of 1.5 million prior to the COVID-19 pandemic (and an annual economic impact of \$36–51 billion) could rise to between five and nine million people. This would incur an annual US economic impact of \$149 to \$362 billion in medical expenses and lost income, exclusive of other costs, such as disability benefits, social services, and lost wages of caretakers [25].

Considering the health-related quality of life (HRQoL) ME/CFS demonstrates a significant negative impact on general health, physical functioning, emotional health, vitality, cognitive health, and well-being, in different populations [12, 26–32]. Various tools are used to elaborate the HRQoL, such as EuroQoL-5 Dimensions (EQ-5D-3L) [26, 31] and (EQ-5D-5L) [12], 36-Item Health Survey (SF-36) [29, 31], Pediatric Quality of Life Inventory (PedsQL) [28], overall health status reported on a Visual Analogue Scale (VAS) [12, 27, 30], Abbreviated World Health Organization Quality of Life questionnaire (WHOQOL-BREF) [32], completed by people with ME/CFS, and Family Reported Outcome Measure (FROM-16) questionnaire [30, 32], completed by family members. Simultaneously, HRQol widely affected by all post-COVID-19 domains [24] mostly is assessed by EuroQoL-5 Dimension EQ-5D-5L and VAS [33–35].

The predominant score of ME/CFS and PPCS patients' healthcare is related to primary healthcare, given that patients of these syndromes are mostly treated on an outpatient basis [36–39]. The unifying issues for these diseases are also complex and multisystem nature, which requires coordinated integrative multidisciplinary teamwork to achieve treatment goals [34, 39]. Previous research demonstrated significant results of the interdisciplinary approach, such as the "Recovering from COVID" course, which took a whole system, biopsychosocial approach to understanding COVID-19 and post-viral fatigue and was led by an interdisciplinary team consisting of a clinical psychologist, physiotherapist, occupational therapist, dietitian, speech and language therapist, and a personal support navigator [34].

Moreover, COVID-19 is associated with high rates of psychiatric symptoms, including anxiety, depression, fatigue, sleep disruption, and posttraumatic stress, and consistent risk factors for psychiatric symptoms include the history of a psychiatric disorder and female gender [40]. Researchers notified that while the exact etiology remains unknown, and future research is needed, it is now recognized that overlapping symptomology between post-COVID-19 syndrome and ME/CFS provides a promising avenue for the development of post-COVID-19 rehabilitation [34].

Prior to the COVID-19 pandemic, it was assumed that primary care transformation will usher in a new era of advanced team-based care with extensive roles beyond the physician to build authentic healing relationships with patients [41]. The pandemic hampered the development of primary healthcare, with an emphasis on the hospital sector, but some achievements remain topical. In the context of integrity, the integrative and patient-centric view argues strongly that populations with physical, developmental, or cognitive disabilities—often with related chronic conditions or complex illnesses—endow the concept of healthcare integration with unique logic and meaning. Vulnerable individuals have complicated and ongoing needs (which frequently are part-medical, part-physical, part-psychological, and part-social), experience difficulties in everyday living, require a mix of services delivered sequentially or simultaneously by multiple providers, and receive both cure and care in the home, community, and institutional settings [42]. These statements mostly are applicable also for ME/CFS and post-COVID-19 conditions.

In order to organize person-centered health services for a growing number of people with multiple complex health and social care needs, a shift from fragmented to integrated health services delivery has to take place. For the organization of governance in integrated health services, it is important to better understand the underlying factors that drive collaboration, decision-making, and behavior between individuals and organizations [43]. There are multiple levels of integrated care, and four levels of health services delivery are investigated more often: the personal, the professional, the management, and the system level [43, 44]. In addition to the different levels, researchers present two crucial dimensions of integration: systemic integration, which includes the coherence of rules and policies in the health system, and normative integration, which comprises the role of shared values in coordination and collaboration [43–45].

In the scope of this research, the authors focus on two central levels of the integrative model—the personal level, assuming the relation with the person-centered approach, and the professional level of collaboration (**Figure 1**).



#### Figure 1.

The research focused on the personal and the professional level of integrated health services for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and post-COVID-19 patients.

The following section provides an example of professional collaboration and patient outcomes in the integrative approach for ME/CFS and post-COVID-19 care.

# 2. Coaching as a supportive tool in integrative primary healthcare of post-COVID-19 and ME/CFS patients

Assuming that an integrative approach positively affects the treatment of chronic multimorbid conditions, this research aimed to identify opportunities to improve the health status of post-COVID-19 and ME/CFS patients by involving a professional coach in healthcare teamwork.

The theoretical foundation of coaching is based on psychological concepts [46]. Several types of models and theories form the basis of behavioral change in coaching. Those most frequently referred to in the literature include the Transtheoretical Model of Change (TTM), the Theory of Planned Behavior (TPB), Social Cognitive Theory (SCT), the Information-Motivation-Behavioral-Skills Model (IMB), Self-Determination Theory (SDT), Health Action Process Approach (HAPA), and Social Learning Theory (SLT) [47]. Each theory is distinct; however, coaching recognizes that individuals intrinsically learn in different ways, and thus the process could involve one or a combination of models or theories which may complement one another [46]. Practical coaching intends to facilitate, support, challenge, and guide a change to achieve a goal [48].

Regarding the coaching experience in healthcare during the COVID-19 pandemic, literature resources identified that COVID-19-specific tele-coaching effectively supported the risk-reduction behavior of patients with heart failure [49] and improved diabetes patients' health behavior [50], as well as coaching promoted medical staff well-being during COVID-19 [51] and demonstrated a positive effect on medical students' well-being [52]. On the whole, there are insufficient studies on the use of coaching in ME/CFS and post-COVID-19 patients.

To evaluate the complementary opportunities provided by coaching in post-COVID-19 in ME/CFS patients' healthcare, the longitude case study was performed in a primary care institution, in Latvia. The professional team consisted of a general practitioner, infectiologist, and coach. The coaching sessions were led by a certified coach of the Erickson Coaching International. Patient-centeredness, patient-determined goals, use of a self-discovery process, accountability, and consistent coaching relationship represent the key elements of coaching. Erickson coaching expands the coaching over and above these elements by strict focus at the solution (i.e. client's determined goal) not only throughout the individual coaching conversation but also throughout the entire coaching relationship (solution-focused Erickson coaching) [53].

Four patients, two ME/CFS and two post-COVID-19 patients with symptoms persistent for more than 6 months prior to diagnosis "Long-COVID-19," were invited to participate in this study. "Portraits" of the patients prepared by the supervising physicians are available in **Figure 2**. Virtual coaching sessions were held for each patient once a week for 4 weeks, in March and April 2022 (two additional sessions were conducted for Patient 2, by her request).

The work steps were devoted to the assessment of patients' HRQoL before and after the coaching course. In order to obtain comparable data for evaluation of the potential impact of the coaching process, HRQoL was assessed using the EuroQol-5D-5L measure (certified translation: EQ-5D-5L Latvian) as the patient-reported outcomes (PROs). The EuroQol EQ-5D-5L assesses HRQoL across five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression [54], and it was mentioned in previous research [12, 33–35]. Prior to the coaching course, patients were asked to assess their health across five dimensions, before the illness and at the present time. Accordingly, after the last coaching session, the patients had reassessed their health status.



#### Figure 2.

"Portraits" of Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and post-COVID-19 patients in the study.

The results of the PROs are shown in **Figure 3** (each dimension of health was scored from 1 (extreme problems) to 5 (no problems)). Descriptive and analytical statistical methods were utilized for the analysis of the obtained data.



#### Figure 3.

Patient-reported health-related quality of life, as measured by the EuroQol-5D-5L framework (1—extreme problems, 2—severe problems, 3—moderate problems, 4—slight problems, and 5—no problems), in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and post-COVID-19 patients: prior illness, prior coaching course, and after 4 weeks coaching course (Patient 2—after 6 weeks).

The results (**Figure 3**) show that Patient 1 (ME/CFS) and Patient 3 (post-COVID-19) demonstrated full-health HRQoL prior to illness, but Patient 2 (ME/CFS) and Patient 4 (post-COVID-19) had the pain and discomfort also before making the

diagnosis. Self-care ability was less affected by the illness—by two points in sum for all patients; usual activities were more affected—by five points in sum for all patients; mobility was affected harder—by six points in sum for all patients; anxiety/depression was activated—by six points in sum for all patients; and pain/discomfort was most accelerated—by seven points in sum for all patients. After the coaching course, PROs demonstrate a stronger impact on pain/discomfort reduction—by eight points in sum for all patients, and on anxiety/depression—by four points in sum for all patients; while mobility was improved—by five points in sum for all patient, usual activities by three points in sum for all patient, and self-care ability—by two points in sum for all patient (self-care ability was less affected by illness).

Additionally, the overall health self-assessment was performed by the VAS. Prior to the coaching, patients were asked to rate their health on a scale from 0 to 100 (where 0 means the worst health patient can imagine, and 100 means the best health patient can imagine), before the illness and at the present time. Accordingly, after the last coaching session, the patients had reassessed their health status. The results of the PROs by the VAS are shown in **Figure 4**.



#### Figure 4.

Patient-reported health-related quality of life, as measured by the Visual Analogue Scale (0—the worst health patient can imagine, and 100—the best health patient can imagine), in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and post-COVID-19 patients: prior illness, prior to the coaching course, and after 4 weeks coaching course (Patient 2—after 6 weeks).

PROs by the VAS (**Figure 4**) show that all patients reported a significant reduction in overall health status due to illness: Patient 1 (ME/CFS)—by 40%, Patient 2 (ME/CFS) and Patient 3 (post-COVID-19)—by 20%, and Patient 4 (post-COVID-19)—by 15%. After the coaching period, all patients demonstrated an improvement in overall health status by more than half: Patient 1 and Patient 2—by 30%, Patient 3—by 20%, and Patient 4—by 10%. Remarkably that ME/CFS patients reported greater improvement in overall health, and Patient 2 reported a higher score of overall health after the coaching course than it was before the diagnosis of illness.

In order to obtain more information on the health status of patients during the study, the physicians supervising these patients were also asked to assess patients' health state, prior to the coaching course and after the course. The assessment was

performed by the VAS with a rating on a scale from 0 to 100 (where 0 means the worst health state of the patient, and 100 means the best health state of the patient). Three dimensions of health were defined for evaluation: overall health, emotional health, and cognitive health. The results of the assessment of the patients' health provided by the physicians are shown in **Figure 5**. Significant improvement was indicated in all dimensions of health states for ME/CFS patients in comparison with the health status of post-COVID-19 patients. Notably that the improvement also is greater in ME/CFS patients. Overall health state assessment after the coaching period is correlated with the results of PROs performed by VAS (**Figure 4**) (except for Patient 2 data in which patient's self-assessment after two additional weeks of coaching). The stabilization between all dimensions of health was a common tendency for all patients (**Figure 5**).



#### Figure 5.

Evaluation of the patient's overall health status, emotional health, and cognitive health, measured by the Visual Analogue Scale (0—the worst health state of the patient, and 100—the best possible health state of the patient), in myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and post-COVID-19 patients: prior to the coaching course, and after 4 weeks coaching course.

Overall results of the study demonstrate significant improvement in the health state of ME/CFS and post-COVID-19 patients, particularly, in overall health, emotional stability, and cognitive functionality. However, this case study has limitations, such as the following: data are not statistically significant for extrapolation to the whole population of patients; there are no sufficient data for comparison with data in other countries on coaching approach in healthcare of post-COVID-19 and ME/CFS patients; during the coaching period, patients continued to receive the standard treatment; therefore, coaching could be considered as a complementary tool in an integrative approach, but not as a monomethod. The strength of this research is focused on the great additional opportunity to resolve the problems arising in chronic diseases management, by affective collaboration and integrative approach, particularly, in primary healthcare.

This study can encourage the further investigation of coaching potential in healthcare, to receive more evidence on the effectiveness of this approach. Additionally, more sensitive evaluation instruments could be considered and would facilitate patients' self-assessment of such symptoms as anxiety, depression, fatigue, sleep disruption, and posttraumatic stress. At the same time, patients should be supported by teaching to work with the PROs tools in the process of health self-assessment. Eventually, in the scope of managerial and system level of integrative healthcare, it should be considered that the financing of the integrative approach can face the challenges in countries with strictly limited budget allocation for healthcare and social issues.

# 3. Conclusion

This chapter provided insight into the integrative approach to healthcare, with a particular focus on post-COVID-19 and ME/CFS disorders. Integrated healthcare consists of four main levels of health services delivery: the personal, the professional, the management, and the system level. In the framework of the practical research, the example of integration of coaching in the personal and professional level of primary healthcare of post-COVID-19 and ME/CFS patients demonstrated the potential for improvement in healthcare outcomes.

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# **Conflict of interest**

The authors declare no conflict of interest.

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