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Entretien

Clinical condition, Resuscitation and Medical-Psychological Care of Severe COVID-19 patients (part 2)



État clinique, réanimation et prise en charge médico-psychologique de malades COVID-19 sévères (2^e partie)

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ABSTRACT

Respiratory rehabilitation is the penultimate step in the medical management of patients with severe COPD-19. It is an essential step before patients' returning home, and is usually carried out in specialised Follow-up and Rehabilitation Clinics. When discharged from hospital, patients with post-severe COVID-19 usually progress in their medical condition. However, they may remain frail and have a constant fear of possible deterioration leading to (re)hospitalisation and a return to baseline. Psychological support in this phase can reduce patients' anxiety and increase their motivation to carry out daily rehabilitation activities. This support provides a stable and consistent basis for patients to focus on their progress, leaving the difficulties behind. Being aware of the improvements in their physical condition allows them to maintain their motivation to continue to be physically active. Psychological support during respiratory rehabilitation aims at preparing patients to return to the normal life they had before the disease. It is usually based on brief psychotherapies that focus on strengthening the patient's abilities through behavioural changes and through reducing risk behaviours. Only after this phase is it sometimes possible to deal with complex issues and to cope with personality mechanisms and maladaptive behaviour patterns.

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RÉSUMÉ

La réadaptation respiratoire constitue l'avant-dernier étage dans la prise en charge des patients COVID-19 sévère, une étape essentielle avant de retrouver leur vie quotidienne. L'accompagnement psychologique occupe une place importante dans cette étape. Cette réadaptation s'effectue habituellement dans une clinique de Soins de Suite et de Réadaptation (SSR) spécialisée. On peut généralement affirmer que les patients post-COVID-19 sévère sortis de danger vont progresser. Cette progression peut se décrire à travers le modèle de la spirale ascendante. Ce sont, néanmoins, des patients fragiles, pour lesquels on craint perpétuellement une dégradation rapide des paramètres physiologiques qui risque de les ramener vers une (ré)hospitalisation d'urgence et un retour vers la case de départ. L'accompagnement psychologique empêche les sensations négatives d'occuper le devant de la scène et d'aspirer le patient vers le bas. Il permet de baisser les angoisses et d'augmenter les motivations pour effectuer des activités de réadaptation quotidiennes. De cette manière, cet accompagnement a des retentissements physiologiques

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importants, permettant aux patients de progresser en voie de guérison, malgré certaines séquelles occasionnées par la maladie. Cet accompagnement psychologique permet, également, de préparer les patients à leur retour à la vie d'avant et d'adoucir l'impact traumatisant des souvenirs douloureux. Le patient peut les regarder de nouveau et leur redonner un sens moins troublant. Le travail psychologique vise à rassurer ces personnes qui ont perdu confiance en leur corps. On tend à favoriser des thérapies brèves qui mettent l'accent sur les renforcements des capacités, sur les changements comportementaux et le sevrage des produits, avant d'agir sur les mécanismes de coping et sur les schémas inadaptés plus profonds.

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1. Introduction

Medical knowledge about the management of patients treated for COVID-19 has been steadily developing since the beginning of the epidemics, accumulating into a substantial structure [6,19,20,26,30,32,39,45,50]. It covers the various treatments of the disease in its different phases, from prevention to resuscitation and towards community care [5,7,9,28]. Pulmonary rehabilitation is the penultimate phase of medical expertise in the management of post-severe COVID-19 patients. For a large part of these people, it is an essential step before returning to daily life. Pulmonary rehabilitation in France is most often carried out in specialised Follow-up and Rehabilitation Clinics (SSR) where patients are hospitalised on a full ward or outpatient basis for three to five weeks. Psychological support plays an important role in this stage.

This interview with Jean-Pierre Bouchard is the second in a series of two [27] in which Zeev Maoz, Isabelle Huet and Jean Luc Sudres discuss the somatic and mental condition and rehabilitation of severe COVID-19 patients who have undergone resuscitation. This part discusses the condition of these patients after discharge from hospital, during which phase some of them will return directly to their life in the community, while others may benefit from hospitalisation in pulmonary rehabilitation.

Zéév MAOZ is a psychologist at Saint-Orens Cardiovascular and Pulmonary Rehabilitation center (near Toulouse), where he provides psychological support to COVID-19 patients undergoing rehabilitation at the clinic. He is also an associate research professor at the Jean-Jaurès University in Toulouse. Isabelle Huet is a pneumologist at the Saint-Orens Rehabilitation center. She also has an independent medical practice and provides consultations at her office in Foix. Jean-Luc Sudres is a hospital psychologist. He is also a Professor of psychology at the University of Toulouse Jean-Jaurès.

2. Interview

2.1. Jean-Pierre Bouchard: Can you describe the place and role of pulmonary rehabilitation in the health trajectory of post-severe COVID-19 patients?

Zeev Maoz and Isabelle Huet: After discharge, most post-severe COVID-19 patients are out of danger and can hypothetically resume their daily lives. Nevertheless, a large proportion of them will continue to experience various symptoms for some time, sometimes for months after their hospitalisation. Most of these symptoms are physiological, such as breathing difficulties and fatigue, or pain, but others are cognitive, such as memory problems, mood disorders and concentration problems.

The long duration of illness has challenged the modern medical system. In terms of patient-health providers encounters. It required building up as complete a picture as possible of the patient's condition, going beyond the usual one-off look of the

health care professional. The medical history has to be defined in terms of a therapeutic trajectory in which dots where the health professionals meet the patient are connected to a complete path taken by the patient before and after the crisis points [49]. Each encounter between the health caregiver and the patient constitutes a milestone in the patient's medical trajectory.

This enables a comprehensive anamnesis, i.e. knowledge of the development of the patient's disease and the history of his symptoms prior to the medical collapse, which allows for a correct diagnosis, not only of a specific problem but of a whole range of problems and risks, thus quantifying the therapeutic needs much better. It is thus possible to identify the origin of risks arising from the patient's other problems, whether medical or not [17,37,40,44].

One of the important therapeutic consequences deriving from this systematic perspective is the attempt to link the end of one phase of medical care with the beginning of another, avoiding the patient experiencing "abrupt transitions" that interrupt his or her medical trajectory. Such abrupt transitions can be, of course, the emergency situations, but also the transition from hospitalization in a closed environment to a full discharge into community.

Reintegration of patients into the community is nowadays a main goal of almost all medical care and its final step [15]. This is true for different diseases, especially for patients with major chronic diseases or psychiatric disorders. Returning to the community and reintegrating, as far as possible, into a normal life has many psychological and physical benefits, such as support from relatives, a familiar environment and incentives for activity. However, some patients are too frail, and for others, solutions and adaptations to their living environment are needed.

As described in the first part of this interview, the evolution of patients with respiratory problems can be described through the model of the upward and downward spiral [36]. This image of the spiral is a systemic description [18], which looks at the person from several points of view: physiological, psychological, behavioural, social and others. It emphasises the interdependence between the parts that make up the whole. The idea of spiral dynamics is that each system is an evolving whole and that for each system one can describe the evolution in terms of a spiral. The different spirals evolve in parallel, each influencing the other, pulling it in its direction of evolution. This systematic view considers that acting on one or other of the components of the system allows the whole system to evolve. Similarly, a risk in one or other of the components can weaken the whole system.

While in the intensive care unit, the patient is detached from the outside world, away from disturbances and pressures. He/she is in a passive, infantilised state, constantly monitored by a team about his condition and its dangers. On discharge from hospital, he or she must become as independent as possible, not only in terms of daily functioning, but also in terms of responsibility for his or her condition and actions in the world. The patient must be active, both physically and psychologically, otherwise he or she risks being

drawn into a negative spiral. This abrupt transition of the patient's condition requires the creation of antechambers between discharge from the hospital and the return to everyday life.

Medical rehabilitation tries to create this safe environment that bridges the gap between emergency hospitalisation and the return home. It offers an antechamber for these patients, between their assisted and supervised position and a more or less independent life. Whether it is psychiatric rehabilitation or functional rehabilitation for victims of physical trauma, they all aim to bring the person back into the community in a way that allows him or her to move forward and not to sink, to function and not to be sedentary, to find the strength to cope.

In general, the condition of patients with post-severe COVID-19, once out of danger, will usually improve. However, this description needs to be qualified, taking into account the pre-existing risk factors of the disease and its sequelae. In terms of psycho-social support, some of these patients suffered from social isolation before their hospitalisation, others had very little or no support in their usual living environment. These conditions are likely to negatively affect the physical and medical evolution of the patient, leading to a sedentary lifestyle and social isolation that may lead to a deterioration of physiological parameters, which could be the starting point for a downward spiral. For these frail, post-severe COVID-19 patients that carry significant physical after-effects and/ or insufficient support at home, a stay in pulmonary rehabilitation helps to avoid the downward spiral. They can gradually and safely rebuild their physical strength while feeling psychologically protected, both by the medical and paramedical personnel as well as by the psychological follow-up offered, and thus stabilise their construction of the upward spiral.

The rehabilitation process aims to exploit the positive momentum of the medical recovery process, in a secure environment. Psychological support is provided by the whole health care team and is part of the group dynamics of the patients, each with their own history and pathology, but almost all facing the necessity to make behavioural changes that should be maintained at discharge.

One of the primary objectives of pulmonary rehabilitation is to reactivate the body, strengthening the muscles and preventing their deconditioning. In doing so, rehabilitation provides the physical basis for stabilising the respiratory condition and progressing towards recovery, despite some of the sequelae of the disease. It has been found that patients who are hospitalised or bedridden for a long period of time (more than a few weeks) show symptoms of physical deconditioning, including a significant loss of muscle mass and cardiovascular dysfunction. The absence of essential body movements triggers a progressive deterioration of the entire muscular system, which hinders recovery efforts. Fatigue, due to physical deconditioning, adds to the effects of the initial medical condition, due to the disease, to accelerate towards a negative process. This effect of physical deconditioning accelerates considerably with age.

But, as explained in the previous interview [27], patients may feel that the demands of the medical team to activate their bodies are in contradiction with the natural tendency. The body's natural instinct, when it is frail or after going through a life-threatening situation, tends to save energy, to "rest". It was only in the 1980s that rest was no longer indicated as primary care after hospitalisation, surgery or a long illness. The current recommendations are clearly to mobilise the body and activate the muscles, even minimally, as soon as possible [22]. Medical support during the stay in rehabilitation reassures patients that despite the natural "resistance" of the body, the prescribed activities are necessary for recovery. At the same time, the team listens to the patients and to their concerns and adapts the activities to their rhythm. They can gradually and safely rebuild their physical

strength while feeling psychologically protected by the medical team as well as by the psychological follow-up offered, and thus stabilise the building of the upward spiral.

2.2. Jean-Pierre Bouchard: What are the goals of psychological support during pulmonary rehabilitation and how does psychological work with patients aim to achieve them?

Zeev Maoz and Jean-Luc Sudres: Resuscitation is a psychologically complex experience, which confronts the person with old memories and destabilizes certain deep symbols. The physical pains and life threatening dangers are the elements that evoke the weakness of the body as an envelope supposed to protect one's ego [9,16,47,53]. The intrusion of the virus inside through the respiratory tract evokes the penetrability of the body, and leaves deep anxiety at each moment when one carries out the most common activity, that of breathing.

Psychological support for patients during rehabilitation covers two aspects. The first refers to the patient's immediate past, including the psychological impact of the illness, memories and physical sensations during the illness and especially during the intensive care experience. The second refers to their current experience, during the stay in rehabilitation, looking forward, and encompasses physical improvement and motivational goals, including the life that awaits the person on discharge.

Concerning their experience during emergency hospitalisation, the episode of waking up from resuscitation often leaves difficult psychological traces, especially for intubated people. It creates memories of helplessness and the inability to perform the simplest and most mundane actions, such as speaking. This state induces a sensation of physical regression to early childhood. Patients are bedridden and totally dependent on others, they are unable to express their suffering and are subjected to care that concerns their deep dignity. The reminiscences that arise from this crisis state are triggers for Post-Traumatic Stress Disorder (PTSD) [2,3,5]. Indeed, studies show that about a quarter of patients who have undergone severe COVID-19 would later develop significant symptoms of PTSD [23,35,38,41].

Moreover, post-severe COVID-19 patients were under supervision during the resuscitation phase and subsequent intensive care, spending day and night cut off from the world. In their acute phase, they may have been anaesthetised, usually been given different types of medication that influenced their mental state and sometimes subject to hallucinations. Their physical helplessness and infantilised position increased the feeling of regression and of being in a psychological bubble, "out of reality".

When they arrive in rehabilitation, they are immersed in a social environment in which they meet people and share their daily life with other patients. They may feel, at this point, a destabilising contradiction between this world and the partly imaginary bubble in which they found themselves previously. This experience is difficult to share or explain to others, whether to close friends, relatives, carers or to other patients who have not been through the resuscitation experience. These patients may then feel anxious or even "disconnected" from reality.

Psychological work with them aims to reassure them that their psychological fragility is only a temporary condition and not a real pathology (like depression or even psychosis). It helps them to express these conflicting feelings, including memories and images of the state they were in a few days before, and then to reassure them of their normality. During the psychological sessions, patients may be encouraged to describe their condition, their emotions and the sensations they are experiencing, thus preventing negative psychological feelings from invading their whole world. The psychologist may suggest that they explain some of the images and hallucinations they experienced during and after the

resuscitation. Giving meaning to these memories reduces the emotional and anxiety-provoking charge they can induce. Patients can appropriate them, thus avoiding the formation of "black holes" that they cannot integrate into their memory system.

Some patients wish to exploit this unusual state of emotionality and lowered psychological defences to go further in this psychological investigation and invoke memories and situations from their past life related to weakness and pain. They question the meaning of the trauma they have experienced and try to understand the links between this phase and other experiences in their lives, other traumas or bereavements awakened by this experience.

Patients should be encouraged to go beyond mere support and reach out to different layers of their lives. They can make connections between their experience during the disease and other events in their lives, particularly other medical events, traumatic experiences and relational and psychosocial situations that they experienced before becoming ill. The psychological work on traumatic events consists of linking them to what preceded and followed them, thus ensuring continuity and avoiding rupture in the person's life. This continuity is based on stability, i.e. stability of the body, sources of pleasure and social relationships.

However, during the rehabilitation phase post-severe COVID-19 patients cannot be considered as suffering from a Post-Traumatic Stress Disorder (PTSD). PTSD should only be diagnosed at least one month after the traumatic situation (symptoms occurring less than one month after the trauma can be diagnosed as Acute Stress Disorder) [8]. Post-severe COVID-19 patients usually approach their rehabilitation stay very soon after their painful experiences have taken place. In fact, for these patients, even the acute stress disorder cannot yet be diagnosed, as the traumatic event is still ongoing. They still suffer from physical pain and have a constant sense of life-threatening danger.

Thus, total desensitisation work, as proposed for PTSD patients, and re-exposure to trauma stressors are generally not part of the psychological support during the rehabilitation of post-severe COVID-19 patients. However, work on memories related to traumatic events can already be initiated [10]. The aim at this early stage is to prevent these memories from becoming threatening and thus to prevent the patient from developing PTSD later on. For example, Eye Movement Desensitization and Reprocessing (EMDR) [31,42,43,48] therapy offers different tools based on strengthening positive resources while allowing the patient to express feelings and memories. Similarly, Cognitive Behavioural Therapies offer relaxation and mindfulness to help people deal with the traumatic experience and integrate the difficult memories [1–3,12,21,24].

Psychological support during rehabilitation can reduce patients' anxiety and increase their motivation to perform daily rehabilitation activities. Motivational goals are powerful psychological tools for physical effort and progress and body activation. Focusing on patients' motivations enhances their progress. The psychological perception of physical progress is important to encourage activation and effort, and to reduce patient anxiety. This is particularly true when progress is small, from day to day, sometimes inconsistent and not in all expected areas. Thus, the perception of progress often requires defining micro-goals that make micro-progress perceptible. As rehabilitation structures are multidisciplinary, the psychologist can collaborate with other professionals in the team and has access to certain parameters that allow this progress to be quantified.

For example, one of the most common indicators of progress in patients with post-severe COVID-19 is the therapeutic oxygen requirement, both during activity and at rest. The decrease in oxygen dependency is a very palpable physical parameter for the patient that indicates the recovery of his or her lungs. It is also one

of the parameters that distinguish the most post-severe COVID-19 patients from chronic respiratory diseases such as Chronic Obstructive Pulmonary Disease (COPD) patients. While the latter experience a gradual decline in the condition of their lungs, usually with increased dependence on oxygen, post-COVID-19 patients can see a real improvement in their dependence on oxygen, with most achieving full oxygen independence within a month or two after discharge. This is a very encouraging sign for them, as oxygen, for many, is a symbol of the disease, and being free of it represents healing.

Other notable positive evolutions for this population during the rehabilitation relate to physical capacities, measured during activities by force applied (in Watts), distances (e.g. for walking on a treadmill or walking outdoors). Other indicators are the results of different physiological tests, for example the six-minute walk test (6MWT) [14], an easy test to perform by the physiotherapy team, which quickly quantifies the person's physical capacity. Achieving objectives and micro-objectives and being able to quantify one's progress is a source of motivation and pleasure, especially for this population of post COVID-19 patients who were in a serious condition only a few days ago.

The rehabilitation process in sheltered pulmonary rehabilitation centres helps patients to mentally accept the physical efforts required and gives them more time to digest the physical process they are engaged in. In this dynamic of progress, post-severe COVID-19 patients are surrounded during their pulmonary rehabilitation by other patients, some of whom have emerged from similar conditions and are equally motivated to progress. They do not feel alone with their disease, as they probably would if they were at home. This motivating environment creates a real group support dynamic that can protect patients psychologically and reduce the risk of PTSD.

2.3. Jean-Pierre Bouchard: How does psychological support during pulmonary rehabilitation help COVID-19 patients prepare for their return to the community?

Zeev MAOZ: Psychological support in respiratory rehabilitation aims to prepare patients to return to their pre-fractured life. In the idea of getting back to the "old life" are embodied, of course, its pleasures, and the psychological work of accentuating these moments of pleasure as much as possible to increase motivation. However, life before the disease also includes stresses, conflicts and worries, whether for financial or relational issues, either in the family or in the workplace.

The patient's daily life was put on hold for a while. The importance of daily concerns was reduced in the face of the life-threatening situation. But they often remain there, waiting to reappear. These different psychosocial elements, which belong to the personal story of each individual, are the usual field of every psychologist. They cannot be omitted in any kind of rehabilitation work, whether psychological or physical. Patients do not address them at first, but they are an integral part of their story, of their life before and after the illness.

Creating continuity between these elements of the person's daily life and their period of illness allows the parenthesis of the illness to be linked to their life story. It avoids the creation of "black holes" in the person's history, which are the breeding ground for the development of trauma. Within this continuity, sources of stress in patient's daily life, before their disease, must also be integrated, so as not to stress the person further but rather to reassure them that these are not "time bombs" that would explode upon return to daily life.

Indeed, the management of stressful situations was part of the patients' life before their hospitalisation and led to more or less adaptive behaviours. Some maladaptive behaviours can have

consequences on patients' health, and cannot be ignored in the psychological work during rehabilitation. These include risk behaviours such as smoking, eating disorders, use of other substances (especially alcohol) and sedentary inactivity or sometimes hyperactivity. The way a person copes with daily life and handles stressful situations is an integral part of their personality, expressing their coping mechanisms and defences. Hence, once again, the need, even in a specialised rehabilitation setting, to engage in comprehensive psychological work with patients.

However, the limited number of psychological sessions during patients' stay in pulmonary rehabilitation centres (on average three to six sessions) tends to favour work focusing on rapid behavioural changes (Cognitive Behavioural Therapy) before addressing deeper psychological mechanisms. Psychological support can trigger a broad effect on personality through a sequence of small and successful behavioural changes, including increasing the person's self-esteem and confidence in their ability to change [29,51].

Patients' motivation to change is intensified in rehabilitation by the medical setting and their illness. Their painful experience during intensive care and the fact that they have survived a lifethreatening situation facilitate behaviour change. Physical suffering, which for some is related to previous risk behaviours, prepares them to make decisions and commit to changes, which often require a significant motivational investment [34].

This process of behaviour change can be viewed through the model of Prochaska and Di Clemente [25,33], which portrays six phases: *Precontemplation*, no intention to change behaviour; *Contemplation*, awareness of the problem but no commitment to change; *Preparation*, intention to act; *Action*, active modification of the behaviour; *Maintenance*, new behaviour(s) replaces old ones, and *Relapse*, in case of possible failure to maintain the changes. Patients who have survived respiratory decompensation may have already approached the *Action*, or even the *Maintenance* phase, due to their "forced weaning" from risky behaviours (or substances) during resuscitation.

2.4. Jean-Pierre Bouchard: After discharge from the rehabilitation clinic, how is the continuity of health care in post-severe COVID-19 patients maintained in the community?

Zeev Maoz and Isabelle Huet: The patient is discharged from the clinic when the medical team is reassured that the upward spiral has been steadily established. When the patient returns home, further care in the community can build on the foundations laid during his/her stay in rehabilitation.

Internal satisfaction surveys conducted at the clinic show that around 95% of patients are generally satisfied with their stay at the clinic. Thus, thanks to their pulmonary rehabilitation, patients can turn the page of their illness gently. They leave this (too) long period of their life in hospital with some positive memories and feelings, and above all they can remember some of the treatment instructions and retain some of the new physiological and psychological understanding. This softens the memory of these interludes in their lives and makes it easier to integrate the illness into the person's story, thus preventing them from developing post-traumatic stress disorder.

Medical follow-up and care in the community is then entrusted to general practitioners, specialists, paramedics such as nurses [11,46], social workers, psychologists [4,52], as well as associations and other social actors. They continue the work started during the rehabilitation stay, avoiding any interruption and generally with a low risk of relapse. This concern is particularly relevant for physical activities, where a high degree of continuity is required and follow-up is provided by physiotherapists and community health associations.

Community health care providers play an important role in both post-hospital care and secondary prevention [13], i.e. prevention of relapse and re-hospitalisation. To ensure this continuity after leaving the rehabilitation environment, the Saint-Orens clinic maintains care relationships with several associations, including two in particular. The association of former patients of the clinic, offering them the opportunity to train several times a week for short sessions under the supervision of the clinic's physiotherapists, who are familiar with their initial problems; and a regional association specialises in ongoing respiratory rehabilitation work in the community. This association offers follow-up at home or group activities with the support of various professional care partners who follow the patients: doctors, physiotherapists, dieticians and psychologists.

Disclosure of interest

The authors declare that they have no competing interest.

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