Experiences of improvement of everyday life following a rehabilitation programme for people with long-term cognitive effects of COVID-19

Qualitative study

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Title: Experiences of improvement of everyday life following a rehabilitation programme for people with long-term cognitive effects of COVID-19: Qualitative study.

Abstract

Aim and objectives: To explore challenges in everyday life for people with long-term cognitive effects of COVID-19 and whether a rehabilitation programme contributed to the remedy thereof.

Background: Healthcare systems around the world need knowledge about acute COVID-19 treatment, long-term effects exerting an impact on peoples' everyday lives, and how to remedy these.

Design: This is a qualitative study with a phenomenological approach.

Methods: Twelve people with long-term cognitive effects of COVID-19 participated in a multidisciplinary rehabilitation programme. Individual semi-structured interviews were made. Data was analysed thematically.

Results: Three themes and eight sub-themes emerged with respect to everyday life challenges and experiences of the rehabilitation programme. The themes were 1) Personal insight and knowledge, 2) Changed daily routines at home, and 3) Coping with working life.

Conclusion: Participants experienced long-term effects of COVID-19 as cognitive challenges, fatigue and headaches, which affected their everyday lives, i.e. inability to overcome daily tasks at home and at work, maintaining family roles and relations to relatives. The rehabilitation programme contributed to a vocabulary and insights related to long-term effects of COVID-19 and the experience of being a different person. The programme contributed to changes in daily routines, organizing breaks in everyday life and explaining challenges to family/relatives and the way in which they affected daily routines and their role in the family. In addition, the programme supported several of the participants in finding the right workload and working hours.

Relevance to clinical practice: We recommend multidisciplinary rehabilitation programmes inspired by cognitive remediation of long-term COVID-19 cognitive effects. Municipalities and organizations could collaborate in the development and completion of such programmes, possibly comprising both virtual and physical elements. This could facilitate access and reduce costs.

Patient or Public Contribution: Patients contributed in the conduct of the study by participating in the data collection via interviews.

Keywords:

COVID-19, long-term effects, cognition, rehabilitation, everyday life, working life

What does this paper contribute to the wider global clinical community?

- Knowledge of challenges in everyday life, including working life, for people with long-term effects of COVID-19.
- How a rehabilitation programme can help people with cognitive long-term effects of COVID-19.

1 Introduction

Worldwide, the COVID-19 outbreak and pandemic has affected a considerable number of persons and, as at the beginning of December 2021, the number of confirmed infections with the virus, SARS-CoV-2, is counting more than 263 million cases and over 5 million deaths (World Health Organization, 2021c), despite vaccination programmes. In addition, the COVID-19 pandemic made it clear to healthcare systems around the world that knowledge is required, not only about acute treatment and care of the disease, but also about the long-term effects of COVID-19 (Malik, Zaidi, Iqbal, Khan, Ali, Rana, Waqar & Ishaq, 2021; Missel, Bernild, Christensen, Dagyaran & Berg, 2021).

2 Background

More than 100 symptoms related to COVID-19 are reported in studies of which fatigue, shortness of breath, muscle and joint pain, sleep disturbance, headache and cognitive influences are the most common (Malik et al., 2021; Martimbianco, Pacheco, Bagattini & Riera, 2021; Rasmussen, Jørgensen, Backmann, Elnegaard & Rottmann, 2021). More persistent long-term COVID-19 effects are found with impaired cognitive function, manifested by fatigue and problems with concentration and memory, being among the symptoms suffered by many, thus impacting peoples' everyday lives including their work lives (Ahmed, Patel, Greenwood, Halpin, Lewthwaite, Salawu, Eyre, Breen, O'Connor, Jones & Sivan, 2020; Bliddal, Banasik, Pedersen, Nissen, Cantwell, Schwinn, Tulstrup, Westergaard, Ullum, Brunak, Tommerup, Feenstra, Geller, Ostrowski, Grønbæk, Nielsen, Nielsen & Feldt-Rasmussen, 2021; Iqbal, Lam, Sounderajah, Clarke, Ashrafian & Darzi, 2021; Lopez-Leon, Wegman-Ostrosky, Perelman, Sepulveda, Rebolledo, Cuapio & Villapol, 2021). This is supported in international systematic literature reviews demonstrating that people having been ill with

COVID-19 experienced different challenges in relation to functioning and activities of their daily lives (Lopez-Leon et al., 2021; Malik et al., 2021; Martimbianco et al., 2021).

Guidelines as to how post COVID-19 rehabilitation should be conducted emerged in the course of the pandemic (Barker-Davies, O'Sullivan, Senaratne, Baker, Cranley, Dharm-Datta, Ellis, Goodall, Gough, Lewis, Norman, Papadopoulou, Roscoe, Sherwood, Turner, Walker, Mistlin, Phillip, Nicol, Bennett & Bahadur, 2020; National Institute for Health and Care Excellence, 2022; World Health Organization, 2021a). Studies suggest that the conduction of rehabilitation programmes should address how to cope with the common symptoms of fatigue, affected memory and concentration (Backmann, Maribo, Zwisler, Davidsen & Rottmann, 2021; Bliddal et al., 2021). Also, in "COVID-19 Clinical Management", the World Health Organization (WHO) recommended that patients experiencing problems with memory, concentration and problem solving should be offered psychoeducation in order that their expectations relative to own levels of functioning be lowered and thus prevent worrying, stress, anxiety and restlessness. The WHO also recommended that patients should be supported in their participation in meaningful activities (World Health Organization, 2021a). However, studies of rehabilitation programmes addressing cognitive problems and the way in which persons with post COVID-19 effects could manage their everyday lives are sparse. A study of 30 individuals presenting COVID-19 symptoms completed a six week rehabilitation programme and demonstrated significant improvement in walking capacity, respiratory symptoms, fatigue and cognition (Daynes, Gerlis, Chaplin, Gardiner & Singh, 2021). To the best of our knowledge, however, no studies have been conducted on how to understand challenges in everyday life, including working life, for people suffering from long-term cognitive COVID-19 effects or on how rehabilitation programmes may support to remedy such challenges. Based on this, The Danish Knowledge Centre for Rehabilitation and Palliative Care (REHPA) conducted a rehabilitation programme for the purpose of helping people suffering from long-term

effects of COVID-19, in particular cognitive problems. The aim was to explore challenges in the everyday lives of people with long-term cognitive effects of COVID-19 and whether a rehabilitation programme contributed to the remedy thereof.

3 Methods

3.1 Design

Due to the aim, a phenomenological qualitative study was chosen to describe the significance of how people suffering from long-term cognitive effects of COVID-19 will experience challenges in their everyday lives and the participation in a rehabilitation programme. To get insight into a common meaning (Earle, 2010), we aimed at gaining knowledge about as well as describe how this was experienced and understood from the perspective of the participants.

'The consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups' (Supplementary File 1) have structured the article (Tong, Sainsbury & Craig, 2007).

3.2 Concepts

Rehabilitation is an essential part of universal healthcare coverage along with the promotion of good health, prevention of disease, treatment and palliative care. Rehabilitation is defined as *"a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment"* (World Health Organization, 2021b). In this programme, our understanding of rehabilitation has been inspired by the concept of cognitive remediation (Bruun & Hauptmann, 2021). Cognitive remediation is a neuropsychological treatment aimed at encouraging a person's own resources and to overcome cognitive disabilities. Cognitive remediation is an overall concept, where the mechanisms of action are exercise, function practice and compensating strategies. Psychoeducation also constitutes an element in cognitive remediation,

pointing towards the development of metacognition, which improves the person's awareness of own cognitive possibilities and limitations (Bruun & Hauptmann, 2021).

The concept of everyday life includes a person's working life and is understood as a relational and interactive concept which, among other things, includes relations, actions, daily routines and time perspectives (Bech-Jørgensen, 2005; Schutz, 1975). These broad concepts contributed to shaping the rehabilitation programme and interview guide, data collection and analysis.

3.3 Setting and the intervention

This study consisted of a rehabilitation programme for people experiencing long-term effects of COVID-19, e.g. cognitive challenges and fatigue, and was developed and conducted at the REHPA research clinic. Among its research and development activities, REHPA arranges multidisciplinary rehabilitation programmes for people with life-threatening diseases. REHPA has developed a standard-model for these programmes (Figure 1) which consists of a five-day residential stay followed by a two-day follow-up stay taking place approximately 12-weeks later (Rasmussen, Jespersen, Backmann & Jarlbæk, 2020).

[Insert Figure 1].

The REHPA standard rehabilitation programme which uses group sessions and individual counselling that addresses physical, psychological, social and existential conditions, was also the framework for this rehabilitation programme. Thus, this rehabilitation programme, inspired by the concept of cognitive remediation, was adjusted to fit the target group and included needs assessment, neurocognitive screening, cognitive training, compensatory tools, energy conservation, psychoeducation and methods to and training in the management of everyday activities in life and work life. The psychoeducational interventions in this programme draw on knowledge from the field of neurology, our own rehabilitation experience within the field of cancer and the early

recommendations from WHO, thus falling into three parts: knowledge of brain function, compensatory strategies and cognitive training (Kristensen & Nielsen, 2011; Wæhrens, Winkel & Jørgensen, 2013).

In this rehabilitation programme, we focused on interventions which could support the participants' everyday lives. Participants were encouraged to work with own goals, apply knowledge from their residential stay as well as virtually accessible exercises during their at-home period. Table 1 shows the elements of the rehabilitation programme.

[Insert Table 1].

3.4 Recruitment and participants

The recruitment of participants to the rehabilitation programme took place via website, networking, newsletters, social media and contact with infectious-disease wards at hospitals in Denmark. Participation in the programme required referral by the patients' general practitioner or a hospital doctor and internal visitation by a nurse and an occupational therapist at REHPA. Visitation criteria were people diagnosed with COVID-19 (PCR test and/or antibody test) who had either been hospitalized or isolated at home and who experienced cognitive problems such as memory and concentration trouble, which affected working life, activities in everyday life and quality of life. During the period from January to September 2021, there was a total of five COVID-19 residential intervention stays of five-days each, followed by 12 weeks at home and a two-day follow-up on the residential stay. This study is based on the participants in one of these five residential-intervention stays.

3.5 Data Collection

The specific method used were individual semi-structured interviews (Brinkmann & Tanggaard, 2015; Kvale & Brinkmann, 2009), and each participant was only interviewed once. Thus, the

participants' experiences of long-term effects of COVID-19 including cognitive problems and experiences from their participation in the rehabilitation programme at REHPA were explored. The interviews provided an opportunity to concentrate on the way in which specific individuals understand specific events and situations in their own lives (Brinkmann & Tanggaard, 2015). The interview guide (Table 2) covered the study aim, the understanding of concepts in rehabilitation, cognition and everyday life (Kvale, 1998).

[Insert Table 2].

Interviews were conducted on the last day of the follow-up to minimize recall bias. Six health professionals (two clinicians, two PhD students, one senior researcher and one clinician leader) from REHPA conducted the interviews. Interviews were digitally recorded and transcribed verbatim by two student assistants with transcription experience. The first author checked the transcriptions of each interview.

3.6 Data analysis

An inductive thematic data analysis was carried out (Braun & Clarke, 2006; Dierckx de Casterlé, Castmans, Bryon & Denier, 2021; Thomas, 2006). However, the concepts of rehabilitation, cognition and everyday life have inspired and given direction to the analysis. Thus, statements related to *functioning* and *exercise perspectives* referred to rehabilitation (World Health Organization, 2021b) whereas statements about *relations, interaction, routines* and *time perspectives* referred to everyday life (Bech-Jørgensen, 2005; Schutz, 1975).

Specifically, the thematic analysis was structured according to Braun and Clarke's six phases: 1. Becoming familiar with the data: The interview transcripts were read and checked for accuracy against the audio recordings if something was unclear. 2. Generating initial codes: Transcripts were analysed and open-coded (paper and pencil). Statements in the interview transcripts contributed to the development of abstract and conceptual codes, which were compiled into a code list with

reference to page numbers in the interview transcripts. 3-4. Searching for and the review of themes. 5-6. Defining and naming themes and writing the article (Braun & Clarke, 2006). All authors discussed the themes, which resulted in linguistic changes. An example of phase two to six is accessible in Table 3.

[Insert Table 3].

3.7 Ethical Considerations

Data collection and the processing of data are approved by the Region of Southern Denmark (file number: 20/46585) and comply with the Helsinki Declaration II for informed consent, anonymity and the opportunity to withdraw from the study (World Medical Association, 2018). Prior to the rehabilitation programme, the participants received an information leaflet describing the study, including the aim, the data collection and the opportunity to withdraw from the study. The information was repeated at the beginning of the rehabilitation residential stay. All participants agreed to participate and gave their written consent. Anonymity is ensured by refraining to mention names, age, gender and profession in the interview quotes.

4 Results

Thirteen individuals participated at the follow-up stay, i.e. were eligible for participation in the interviews. However, one participant had to leave the programme prior to the interviews owing to family issues at home. Hence, twelve participants were interviewed, eight women and four men at an average age of 50. Table 4 presents demographic and clinical characteristics relating to the participants.

[Insert Table 4].

The interviews lasted between about 40 and 60 minutes. Three themes and eight sub-themes emerged from the interview data (Table 5).

[Insert Table 5].

4.1 Personal insight and knowledge

All participants mentioned that the rehabilitation programme had helped them gain personal insight and knowledge about being ill. One participant said:

> *"Finally, to be seen as someone who was ill. This was an extreme eye-opener and an opportunity to do something different and to be seen for what one was"* [11].

The personal insight and knowledge regarded three sub-themes: "being ill and suffering from long-term effects", "not being the same person", and "it takes time to heal".

All participants talked about the first sub-theme "being ill and suffering from side effects". They explained how they had memory trouble, and some of the participants [2, 6, 7, 9, 12] used wordings such as *"not being able to think coherent thoughts", "not being able to express oneself", "words that disappear"*, and *"memory loss".* In addition, the participants talked about physical problems such as trouble with respect to smelling, sleeping, balance, bodily distress, shortness of breath, fatigue and headache. One participant said about headache*: "I can feel when the headache is coming, and then I can't participate in more that day"* [9] and, about smelling problems, another said: *"I can't smell anything. Why is that?"* [2].

During the residential intervention, presentations, cognitive tests, individual dialogues with health professionals as well as within the community of fellow participants contributed to a better understanding of the individual's own situation. All but one participant [4] expressed how the presentations had provided new knowledge about COVID-19, long-term effects and the existential, physical, psychological and cognitive challenges related to COVID-19 and the way in which to create a good work life. This knowledge contributed to the recognition and acceptance of oneself

but also to a new vocabulary about having suffered from COVID-19 and long-term effects. Two participants said:

> *"Knowledge helps me with my own recognition"* [7].

> *"I've gained a completely different vocabulary and a much better understanding [ed. of my situation]"* [12].

All but one participant [4] talked about how the cognitive test on an evidence-based background proved that they were ill with COVID-19 and were suffering long-term effects. One participant said:

> *"The cognitive test was very important to me. It gave a picture, evidence, a physical thing which showed and measured that I am ill"* [3].

Some of the participants [2, 3, 5] stressed that the individual dialogues with health professionals had been valuable. They felt they were listened to and that this conversation was motivating. One of the participants said: *"[…] and the relaxed conversation with XX, who listened and came up with great suggestions"* [2].

The personal insight and knowledge also regarded a sub-theme "not being the same person" and several of the participants [2, 3, 4, 6, 7, 9, 10] touched upon this subject. Two participants said:

> *"I'll not be the person I was before, but I'll get well again. […] I was the one they could always call in case of problems. After the disease, I can no longer fill this role. I've become a different person. I don't have the energy"* [2].

> *"I probably see myself as a person with fewer resources but, nonetheless, I'm the same person"* [7].

These quotes show the future changes expected by the participants with respect to less physical and mental energy. It involved an insight into and knowledge of "*a need to prioritize health"* [2], *"loss of personal roles and work identity"* [10] and having to rely on help from other people. Thus, one participant said: *"I've been a mother for so many years and been used to help others. So, letting others carry out some of the tasks for me – it's been difficult"* [9].

Several participants [2, 4, 7, 6, 8] said that their recovery took time (sub-theme three). This insight and knowledge was significant in terms of "*showing self-respect and self-care*" [7] and not having relapses:

> *"Now, I don't need the occupational therapist, now I'm in control. Then I had a substantial setback. Then the occupational therapist said to me: We keep going. You keep going with me"* [2].

4.2 Changed daily routines at home

All participants said that the insight and knowledge had contributed to changes in their daily routines with regard to "priorities" (sub-theme one), "breaks during the day" (sub-theme two), and "family members and close relatives" (sub-theme three).

The prioritization sub-theme was based on the fact that several participants [2, 3, 4, 5, 6, 10] expressed a need to deal with fatigue, a pronounced long-term effect in everyday life. Two participants said:

> *"I soon get tired, lack concentration and attention […]. It has to do with energy management – you can't do it all"* [6].
>
> *"That fatigue – my body swallows me up"* [3].

The prioritization theme concerned the way of downscaling demands made on oneself, especially with respect to physical exercise, practical work in the home such as gardening and hoovering, distributing the practical tasks over the day, and to say no and/or prioritize the number of commitments to others. One participant said:

> *"In general, I think that every day I just have to remember: if I have three commitments, I shouldn't make any more, and probably not tomorrow either"* [12].

Prioritizing also concerned meeting challenging situations with caution. One such example is about a participant who would become dizzy when crossing bridges, trying to overcome the situation as follows:

> *"I just have to stand on the bridge and look at the water. Then I need to take a step back and look at the bridge – not at the flowing water – and then I was actually able to walk over the bridge* [2].

All participants reported that the rehabilitation programme helped them recognize the need for breaks in the course of the day (sub-theme two). Such breaks were most frequently scheduled and structured: *"For me, it works well with those three breaks a day"* [9], one participant said. The participants reported the breaks to be either relaxing exercises such as mindfulness, breathing exercises and yoga, or physical exercises such as cycling and walks in the nature. These breaks helped the participants, who suffered from long-term effects such as fatigue, memory problems and headaches, to conserve their energy throughout the day. Two participants said:

> *"I got a lot out of the brain breaks and found out how to get rid of my headache"* [12].

> *"I start my day with a walk and gather energy"* [2].

It was, however, important to balance breaks with relaxing and physically challenging exercises. Thus, one participant said:

> *"We began by cycling and small intervals [ed. in the municipal rehabilitation programme]. Then the exercise with the chair and a bit of weightlifting. Afterwards, I couldn't walk or cycle for a week – back pain, headache, and my whole body was exhausted. Then I dropped out of the programme. Right now, I do yoga exercises – feeling my body, breathing exercises without having to exert myself. I need to be physically active, without overdoing it"* [5].

According to several of the participants [2, 3, 5, 6, 7, 8, 10, 11, 12] the rehabilitation programme helped them explain their long-term effects to their family and close relatives and how they affected everyday routines and roles in the family (sub-theme three). Two participants said:

> *"The programme has given me knowledge of how to explain to others why I do as I do when I get a headache. I've used it with my family and some friends who don't really understand long-term effects"* [12].

> *"I bought that book [ed. recommended at the rehabilitation programme]. The book was passed around in the family. Their having read the book gave them a deeper understanding of the disease – of why I've changed and why I do this or that"* [2].

The condition was difficult for the family and close relatives to understand in connection with their experiencing how a family member/relative would change personality as well as their increased need for breaks and not being able to cope with daily life as earlier: *"It was hard for the family. They'd say, 'Are you angry or what? Why do you do that?' Then I'd say, 'No, I'm not mad. It's just that I don't have any energy left'"* [2]. This situation was also difficult for the participants: *"When I feel I'm not useful and that I can't do anything in my everyday life, then I also get a guilty*

conscience towards my loved ones" [5]. Experiences of changed roles were related to not being a strong person anymore and not being a person from whom others could receive help. Now, the participants were the ones who had to ask for help in their everyday lives:

> *"So what about being dependent on others. I'm not a fan, but it was necessary because I could not do it myself. I was constantly dependent on someone to drive [ed. the car]. It was a new role"* [10].

4.3 Coping with working life

All participants except one [8] spoke about coping with working life while being affected by COVID-19 long-term effects. Two sub-themes emerged: "adequate reduction in working hours and work assignments" and "insufficient reduction in working hours and work assignments".

In relation to the first sub-theme, the employers at the workplace supported the participants and adapted their job assignments to their level of functioning. Partly by adapting work assignments in terms of quantity and complexity and reducing working hours, and partly by easing workloads and responsibility with respect to the participants.

> *"I can handle 20 hours of work per week. It helps me a lot. I only take on easy assignments and one thing at a time"* [3].

> *"In my work I don't have to take responsibility for anything, there's no sudden pressure. She [ed. the manager] knows I have challenges. I can't take on overtime work. In can't cope with stress and I must not be responsible"* [2].

The participants considered these opportunities at the workplace as a part of their rehabilitation: *"If they [ed. the management] had not supported me, then I'd not be where I am now. I consider my work to be part of my rehabilitation"* [3]. On the other hand, the scaling down and the work effort was also difficult and might also be experienced as pressure:

> *"I have to remind myself that it's OK. I feel guilty when the others have to work hard and I have to sit down. However, nobody looks askance at me. My colleagues said: "You just relax". I'm just imagining things"* [6].

The following elements of the rehabilitation programme especially helped the participants to scale down their work: General material on COVID-19 and long-term effects, the cognitive tests, descriptions prepared by health professionals about the individual challenges experienced by the participants due to long-term effects, as well as the individual dialogues with the health professionals. These elements helped to find the right number of working hours and assignments – either directly in relation with the employer or indirectly via, for example, a municipal job consultant or a general practitioner. One participant talked about the cognitive test results:

> *"At first, I was upset [ed. about the result of the cognitive test]. However, it actually meant something in relation to my employer. I could demonstrate, in cold print [ed. on paper], these are the facts [ed. that I am ill]"* [7].

The second sub-theme "insufficient reduction in working hours and work assignments" focused on the participants experiencing how employers would either pressure them to return to unchanged workloads, working hours and assignments, or on how they were nervous about being fired if they were unable to do so. One participant spoke about returning to work – to unchanged working conditions:

> *"Otherwise, I should just let myself be fired, but I think I'm losing too much. I work nights, every other week. I've done so for 30 years. When working, I feel the week will never end. Sometimes I can't get out of bed, but I go to work anyway"* [4].

This quote also shows how difficult it can be to leave the job market. Another participant talked about being fired due to COVID-19 and long-term effects: *"I thought, 'If I'm fired, I'm fired', but*

when it happened, it was absolutely horrible" [12]. Other participants had to report sick [11] or take early retirement [5].

5 Discussion

All participants experienced the long-term effects of COVID-19 as cognitive challenges, how fatigue and headache would challenge their everyday lives in respect of not being able to overcome daily tasks at home and at work, maintain their usual family roles and relations to relatives. The rehabilitation programme contributed to the provision of a vocabulary, insight into and knowledge of being ill and suffering from COVID-19 long-term effects. In addition, the programme contributed to the provision of an insight into the state of not being the same person anymore, that recovery takes time, and a need to show self-respect by prioritizing their health and conserving energy. The programme helped the participants change their daily routines, e.g. downgrading domestic practical tasks and the number of daily social commitments. Thus, the participants organized several breaks in their everyday lives, e.g. mindfulness, breathing exercises, yoga, and walks. In addition, the programme helped the participants to explain their challenges to family and relatives as well as how this affected their daily routines and their roles in the family. The COVID-19 long-term effects also affected the participants' working lives and several had to downscale their work. The material on COVID-19 and long-term effects, the cognitive tests and the written descriptions by and individual dialogue with the health professionals helped them define the right workload and working hours in cooperation with managers and the municipal employment agency and other municipal professionals. However, a few participants were pressured by the managers to return to unchanged workloads, which contributed to restlessness and fear of being fired.

In general, rehabilitation with focus on cognitive problems includes different therapeutic interventions, based on various psychological and behavioural theories, for the purpose of achieving functional changes (Mantovani, Zucchella, Bottiroli, Federico, Giugno, Sandrini, Chiamulera &

Tamburin, 2020). The rehabilitation programme was inspired by Bruun and Hauptmann's concept of cognitive remediation (Bruun & Hauptmann, 2021). Bruun and Hauptmann divided their remediation programme into eight different modules/sessions. These modules are: 'Introduction to cognition and cognitive remediation', 'Mental speed', 'Attention and concentration', 'Learning and memory', 'Executive functions', 'Cognition and emotions', 'Relatives' and 'Booster' (follow up). The module topics are very similar to ours, though they include more cognitive exercises and more time for each topic, which provides the participants with more experience with respect to different topics and perhaps increased empowerment (Bruun & Hauptmann, 2021). A wider module-based cognitive remediation programme might increase participants' action competence, which is often the goal in health programmes (Simovska & Jensen, 2012). Bruun and Hauptmann also argue that the individual participants need different cognitive programmes and not all modules are relevant for all participants. They discuss individual versus group sessions and find both relevant for participants, just as we experienced in our rehabilitation programme. In our rehabilitation setting, the participants had different sessions compressed into one week, went home for 12 weeks with individual plans and goals and then came back for two days' follow-up. In our experience, it can be difficult for participants to work with their goals and exercises on their own during the 12 weeks at home. Brunn and Hauptmann recommend one cognitive exercise at a time during the 12 weeks at home rather than several at the same time (Bruun & Hauptmann, 2021). When you want to change your behavioural patterns and habits, home exercises can be essential, e.g. breaks, walks, mindfulness. Behavioural patterns can be difficult to change because very often they are automatic and not perceivable to the person (Bech-Jørgensen, 1994). In the REHPA rehabilitation programme, conservation strategies and focus on daily breaks have been helpful to the participants. However, other rehabilitation programmes focusing on 'automatic actions' and 'goal management training' have shown good results in emotional regulation (Stubberud, Huster, Hoorelbeke, Hammar &

Hagen, 2021). Bruun and Hauptmann also recommend therapeutic guidance in the at-home period with video consultations as a relevant and timesaving instrument in cognitive rehabilitation (Bruun & Hauptmann, 2021).

Studies (Ghadiri, Moghadasi & Sahraian, 2022; Mantovani et al., 2020; Smits, Staal & van Goor, 2020) suggest virtual-/telemedicine as a strategic intervention for rehabilitation programmes targeted at people with COVID-19 long-term effects, with and without other diagnosis. This was presumably, because of the difficulty in predicting a time when the worldwide physical restrictions would be relaxed/terminated and perhaps also because the pandemic opened our eyes to virtual solutions in general. However, as far as we know, no evaluations were made of the significance of virtual or physical rehabilitation programmes for this particular diagnosis group.

Other diagnosis-group studies have shown positive results for rehabilitation programmes (including virtual programmes) with focus on cognitive problems, e.g. with respect to cancer patients (Santos, Hardy-Léger, Rigal, Licaj, Dauchy, Levy, Noal, Segura, Delcambre, Allouache, Parzy, Barriere, Petit, Lange, Capel, Clarisse, Grellard, Lefel & Joly, 2020; Von Ah & Crouch, 2020), early state of dementia (Øksnebjerg, Woods, Vilsen, Ruth, Gustafsson, Ringkøbing & Waldemar, 2019), chronic stroke (Veisi-Pirkoohi, Hassani-Abharian, Kazemi, Vaseghi, Zarrindast & Nasehi, 2019), and the elderly (Montoya-Murillo, Ibarretxe-Bilbao, Peña & Ojeda, 2019). Although this rehabilitation programme for people with COVID-19 long-term effects showed positive results, it must be tested in real contexts, e.g. in collaboration with hospitals and/or municipalities (Sivan, Halpin, Hollingworth, Snook, Hickman & Clifton, 2020).

This rehabilitation programme was conducted as a physical programme, but it is possible that the programme has a potential for being tested as a partially virtual programme in different collaborative contexts. The virtual parts could for instance include presentations – but maybe also networking dialogues with health professionals, and introduction to exercises. Thus, a partially

virtual programme could contribute to the facilitation of access to rehabilitation and include more participants over a longer period. However, it should be considered how long time people suffering from COVID-19 long-term effects, such as headaches, will be able to sit by a computer screen. In addition, it is possible that virtual solutions will reduce COVID-19 rehabilitation costs, which is more expensive as compared with for example cardiac rehabilitation (Iannaccone, Alemanno, Houdayer, Brugliera, Castellazzi, Cianflone, Meloni, Ambrosio, Mortini, Spina & Filippi, 2020). Moreover, a virtual programme could be adapted to the individual's needs with respect to knowledge, daily routines and working life.

5.1 Study strengths and limitations

This qualitative study has both strengths and weaknesses. The study included twelve participants from one of five rehabilitation programmes for people experiencing cognitive COVID-19 long-term effects. The participants were characterized by more women (67%) than men (33%), more married (75%) than single (25%), and more having a medium-length or long academic education (67%) than a vocational (33%) education level. Seven (59%) of the participants were actively employed and four (33%) were on sick leave whereas one was retired. All participants were Danish residents. Thus, the study can be limited to participants reflecting the included population.

All interviews were conducted with participants from one of five rehabilitation programmes. The participants may have influenced one another during the rehabilitation programme by the exchange of stories and experiences prior to being interviewed. Thus, more or different knowledge might potentially have been gained from interviewing two or three participants from each of the five rehabilitation programmes.

Participants could be influenced by recall bias as cognitive challenges by fatigue can affect memory. However, the interviews being held on the last follow-up day contributed to minimize recall bias, thus making the rehabilitation programme as present as possible.

The interviewers being composed by six different health professionals established a background for very diverse interviews, although a semi-structured interview guide minimized the possibility thereof.

Prior to the interviews, two of the six interviewers had contact with the participants during the residential rehabilitation stays, which the other four did not. With respect to the participants who knew their interviewer, there is a possibility of bias on behalf of the participant in favour of the interviewer either wanting to please or refraining from speaking out against the rehabilitation programme. On the other hand, it is possible that a good and trustful relation was established before the interviews – an element which is also important in qualitative interviews.

The study also has strengths. The COREQ criteria for reporting qualitative research were used to guide the writing of the article, increasing the quality and ensuring the provision of relevant information. Being semi-structured, the interviews created an openness towards following interesting paths of the interviews, offering a broad insight to cover all aspects of the aim. It is a strength that the rehabilitation programme was based on existing knowledge and guidelines; and, similarly, it is a strength that the analysis was done inductively, i.e. the participants' expressions guided our conclusions. All participants were interviewed at the same time of the follow-up. Several times, the results showed that more participants talked about the same thing, i.e. a sample size of twelve participants was enough to reach a certain level of data saturation.

6 Conclusion

All participants experienced long-term cognitive effects of COVID-19 such as fatigue and headache challenging their everyday lives with respect to being unable to overcome daily tasks at home and at work and to maintain family roles as before and relations to relatives. The programme helped the participants to change daily routines, to take breaks in their everyday lives, and to explain challenges to family and relatives as well as how this affected daily routines and roles in the family.

In addition, the programme supported several of the participants in finding appropriate workloads and working hours. Thus, this multidisciplinary rehabilitation programme contributed to a vocabulary and insights into suffering from long-term effects of COVID-19 and no longer being the person they used to be.

7 Relevance to Clinical Practice

We recommend multidisciplinary rehabilitation programmes to be developed and conducted for people suffering from long-term cognitive effects of COVID-19. Such programmes may be inspired by cognitive remediation and contain the dissemination of knowledge, breaks, exercises and training, but also networking with other people in the same situation. Municipalities and other relevant organizations could collaborate in the development and completion of such programmes. This could facilitate access to rehabilitation and reduce costs. In addition, the composition of programmes consisting of virtual as well as physical elements should be considered.

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Tables

Table 1. Elements in the cognitive rehabilitation programme.

Neuropsychological testing with individual feedback to participants	Introduction to neuropsychology and COVID-19. Individual screening with neuropsychological tools: Trail Making Tests A and B, WAIS-IV (range of number and symbols of number), RBANS wordlist, five-point-test, fluency-animals 60', s-word 60' and d2 test. Individual feedback from the results of the tests and guidance related to everyday life.
Group sessions about the brain under influence of COVID-19, management of everyday life with cognitive problems, fatigue and energy-conserving strategies	Psychoeducation and dialogue with participants about fatigue and energy-conserving strategies. Psychoeducation about the brain (memory, concentration and everyday life). Education in the training/use of the brain and compensatory strategies.
Take a break in nature	Introduction/education to active breaks in nature. Being out in nature and trying to use the body and mind with guidance from an instructor.
Yoga and mindfulness	Active breaks for brain and mind. Breathing exercises. Practising yoga with an instructor.
Worklife	Optional session – education in current labour legislation and returning to work.
Individual dialogues based on patient-reported outcomes	Before the participant join the programme at REHPA, they fill in a questionnaire with multiple patient-reported outcomes (PRO), thus providing the clinicians with a dialogue sheet. This sheet supports the dialogue with the individual participant an also gets feedback from the cognitive screening and participants' desires with respect to the dialogue. The clinicians were doctors, nurses, occupational therapists, physiotherapists or social workers.
Goal setting with motivational intervention as a framework	The participants make an individual plan and goal setting for their own rehabilitation process. They get a professional feedback on each plan or goal.
Sources of personal meaning in a changing life	The activity uses cards from *'Sources of meaning*[†]*',* which are used in-group sessions. The method is based on extensional type theory and empirical evidence of sources of meaning.
Insomnia	At this session, considerable focus is on sleep hygiene and sleep patterns. Sleep hygiene is focused on the arrangement of the bedroom, temperature, light, and a group dialogue about sleep patterns[‡].

† (la Cour & Frølund, 2017; Schnell, 2009).

‡ (Jennum, Bonke, Clark, Flyvbjerg, Garde, Hermansen, Johansen, Møller, Rod, Sjödin & Zachariae, 2015)

Table 2. Interview guide.

Themes	Questions
The overall programme at REHPA	What were your expectations before coming to REHPA? How did you experience the programme at REHPA? What happened after you got home? Did you change your everyday life? Why or why not? How?
The concrete elements/activities of the programme	At REHPA, there were various activities. What was your experience of these? Did you use the activities at home, and how? Why or why not? How? Which activities of the programme have been particularly important to you? Why? Did you miss anything? Should we have done things differently? Why?
Ending	Do you think there is something we need to talk about?

Table 3. Example of analysis process.

Phase 2 – Initial codes		**Phases 3-4 – Searching and reviewing themes**	**Phases 5-6 – Themes**
Quotes:	**Abstract and conceptual codes:**	**Preliminary theme:**	**Final theme:**
"So, finally to be seen as a person who is ill. This was an extreme eyeopener and an opportunity to do something different and an opportunity to be seen for what one was" [13].	To be and be seen as an ill person	To understand personal changes after a COVID-19 infection	Personal insight and knowledge
"I will not be the person I was before, but I will get well again. […] I used to be the one they could always call should problems arise. I cannot fill this role after the disease. I have become a different person. I do not have the energy" [2].	Another person Impaired functions		
"I probably see myself as a person with fewer resources but I'm still the same" [7].	Recovery		

Table 4. Demographic and clinical characteristics of participants (N = 12).

Characteristics	n (%)	Mean (SD†) [Range]
Age, years		50 (15) [33-77]
Gender, male/female	4 (33) / 8 (67)	
Marital status		
Married or permanent partner	9 (75)	
Single	3 (25)	
Educational level		
Vocational	4 (33)	
Medium-length or long academic education	8 (67)	
Work status		
Employed, full or part time	7 (59)	
Sick leave	4 (33)	
Retired	1 (8)	
Days since COVID-19 diagnosis		233 (102) [139-412]
Hospitalization due to COVID-19, yes	3 (25)	

† Standard deviation.

Table 5. Themes and sub-themes.

Themes	**Sub-themes**
Personal insight and knowledge	• Being ill and suffering from long-term effects • Not being the same person • It takes time to heal
Changed daily routines at home	• Priorities • Breaks during the day • Family members and close relatives
Coping with working life	• Adequate reduction in working hours and work assignments • Insufficient reduction in working hours and work assignments

Figure legends

Figure 1. The standard rehabilitation programme and content.

† REHPA: The Danish Knowledge Centre for Rehabilitation and Palliative Care.