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Understanding recovery of people recovering from COVID-19 receiving treatment from primary care allied health professionals: a mixed-methods study

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ABSTRACT

Purpose: To quantitatively assess changes in recovery of people recovering from COVID-19 treated by a primary care allied health professional, and to qualitatively describe how they dealt with persistent complaints.

Materials and methods: This mixed-methods study is part of a Dutch prospective cohort study, from which thirty participants were selected through purposive sampling. Quantitative data on recovery were collected at start of treatment and 6 months. Additionally, by use of semi-structured interviews participants were asked on how persistent complaints influenced their lives, and how they experienced received primary care allied health treatment.

Results: Despite reported improvements, most participants still experienced limitations at 6 months. Hospital participants reported a higher severity of complaints, but home participants reported more diverse complaints and a longer recovery. Most participants were satisfied with the primary care allied healthcare. Tender loving care and a listening ear, learning to manage limits, and support and acceptance of building up in small steps were perceived as contributing most to participants' recovery.

Conclusion: Although improvements were reported on almost all outcomes, most participants suffered from persistent complaints. Despite these persistent complaints, many participants reported being better able to cope with persistent complaints because they had decreased substantially in their intensity.

Trial registration: Clinicaltrials.gov registry (NCT04735744).

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covid-19; mixed-methods; primary care; allied healthcare; persistent complaints after COVID-19

> IMPLICATIONS FOR REHABILITATION



- Participants recovering from COVID-19 receiving treatment from primary care allied health professionals reported improvements after 6 months, but still experienced persistent complaints.
- Home participants reported more persistent complaints and a longer recovery from COVID-19 than hospital participants.
- Personal attention for patients recovering from COVID-19 is necessary. Next to implementing a treatment plan (e.g. physical exercise), primary care allied health professionals should also pay attention to listening to the patient's story and offering support.
- Interprofessional collaboration between primary care allied health professionals, with a unified message to patients, is essential.

Introduction

Approximately 1 in 8 people will develop persistent complaints after a SARS-CoV-2 infection [1]. People with persistent complaints after COVID-19 experience a wide range of persistent symptoms including fatigue, cognitive problems, respiratory difficulties, and psychological effects such as depression or anxiety [2–6]. Previous studies have shown that people with persistent complaints after COVID-19 felt they were recovering or had recovered, but then

experienced a setback, or they experienced a recurrent cycle of partial recovery followed by deterioration [7,8]. There is a clear sense that people with persistent complaints after COVID-19 experience their persistent limitations as life-altering since they are often unable to resume daily activities as before [5,9–12], they are often unable to return to work at their previous level, or even unable to work at all [9,13].

To help people to cope with the impact of persistent complaints after COVID-19 on daily life, the Dutch government

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arranged the so called “primary allied healthcare regulation”, providing increased reimbursement of primary allied healthcare for a period of six months, with possibility for extension for another six months [14]. This includes increased access to treatment by dietitians, exercise therapists, occupational therapists, physical therapists, and/or speech and language therapists, all fully reimbursed by the health care insurance companies. Simultaneously, a nationwide prospective cohort study was set up to evaluate the recovery trajectories of people recovering from COVID-19 [15]. In a recent publication, we showed that people in this study made progress in their recovery, but still experienced many limitations in their daily activities up to several months after initial infection [16]. Insight into how people in our cohort dealt with these persistent symptoms in their lives, and how they experienced treatment with primary care allied health professionals is lacking.

Therefore, the aim of this mixed-methods study was to quantitatively assess the changes in recovery of people recovering from COVID-19 after intervention by a primary care allied health professional, and to qualitatively describe how they dealt with persistent complaints and how this influenced their lives, and their experiences with received primary care allied health treatment. This mixed method approach allows quantitative results obtained from the measurements and questionnaires to be combined with the qualitative results from the individual interviews.

Methods

Study design

This mixed-methods study is part of a Dutch nationwide prospective cohort study evaluating the recovery of people receiving primary care allied healthcare after a SARS-CoV-2 infection (COVID-19) [15]. Quantitative data on recovery were collected at start of treatment and after 6 months. Participants were included in the quantitative study on average 2 months (range 1–6) after infection ($n = 1,451$). Data on recovery were collected at the start of treatment and after 6 months. From this total cohort, 30

participants were selected and interviewed on average 12 months (range 10–15) after infection. In this mixed methods study, we combined quantitative data of the period between start of treatment and 6 months in these 30 participants, with qualitative data, with the aim to complement and reflect on the combination of results [17]. The parallel mixed-methods approach means that with these 30 participants both quantitative and qualitative methods were integrated to answer the research question to enhance the credibility of the findings [18].

The study protocol of the quantitative study was approved by the medical ethics committee of Radboud university medical center (Registration #2020-7278) and the study has been registered in the clinicaltrials.gov registry (NCT04735744). The study protocol of the qualitative study was approved by the Ethical Research Committee (ECO) of HAN University of Applied Sciences (Registration: 221.12/20). Written informed consent was obtained from all participants.

Participants

For this study, participants (aged ≥ 18 years) who were recovering from COVID-19 infection and were treated by one or multiple primary care allied health professionals (i.e. a dietitian, exercise or physical therapist, occupational therapist, and/or speech and language therapist) were included. Purposive sampling [19] was used to ensure that the sample reflected a heterogeneous group of participants representing treatment by different primary care allied health professionals, as well as variation in characteristics such as age, sex, self-reported severity of COVID-19 (i.e. mild to moderate, severe, or critical, see Table 1 for full definition [15]), hospitalisation during COVID-19 infection, educational level, and geographical area within the Netherlands. We included 18 participants who had not been hospitalised for COVID-19 (home participants) and 12 participants who had been admitted to the hospital (hospital participants).

Quantitative methods

Data collection

The enrolment procedure of the quantitative part of this study is described in detail in the study protocol. In this paper, we used patient-reported outcome data assessed at the start of treatment with one or multiple primary allied health care professionals and after 6 months follow-up:

1. *Physical functioning* was assessed with the PROMIS Physical Functioning Short Form 10b [20]. Total T-scores ranges from 13.8 (severe physically impaired) to 61.3 (not physically impaired), with a mean (SD) score of 50 (10) representing the mean score of a reference population [21]. We categorized differences between the start of treatment and 6 months follow-up into three categories: improvement (increase of ≥ 3.6 points), no changes (change score between -3.6 to $+3.6$), and deterioration (decrease of ≥ 3.6) [22].
2. *Fatigue* was assessed with the Fatigue Severity Scale (FSS), measuring the severity of fatigue and its effects on participants' activities. The score of the FSS ranges from 1 to 7, with a score of 4 or more indicating severe fatigue [23]. We categorized differences into: improvement (decrease of ≥ 0.45 points), no changes (change score between -0.45 to $+0.45$), and deterioration (increase of ≥ 0.45) [24].
3. *Psychological well-being* was assessed with the Hospital Anxiety and Depression Scale (HADS). The HADS is divided

Table 1. General characteristics of included participants.

	$n = 30$
Sex, n (%)	
Male	10 (33)
Female	20 (67)
Age, mean (range)	52 (26-73)
COVID-19 severity*, n (%)	
Mild/moderate	17 (57)
Serious	13 (43)
Very serious	0
Admission to hospital for COVID-19 infection, n (%)	
Hospitalised including IC-treatment	2 (7)
Hospitalised	10 (33)
Not hospitalised	18 (60)
BMI, mean (range)	^a $n = 28$ 29 (18-43)
≥ 25 kg/m ²	20 (71)
Comorbidities, n (%)	
No comorbidities	11 (37)
One comorbidity	9 (30)
Two or more comorbidities	10 (33)
Primary care allied health treatment, n (%)	
Monodisciplinary	11 (37)
Multidisciplinary	19 (63)

Abbreviations: BMI = body mass index; n = number.

*COVID-19 severity defined as: mild to moderate (mild symptoms up to mild pneumonia), severe (dyspnea, hypoxia, or $<50\%$ lung involvement on imaging), or critical (respiratory failure, shock, or multiorgan system dysfunction) [15].

^aData were not fully available for all participants: the n denotes the number of participants with available data.

into an anxiety and a depression score, both ranging from 0 to 21. A total score of 7 or less indicates “no anxiety or depression”. A score ranging from 8 to 10 indicates “possible anxiety or depression” and a score of 11 or more indicates a “probable clinical diagnosis of anxiety or depression” [25,26]. We refer to an improvement or deterioration when a participant was categorized into another category at 6 months from baseline.

4. *Participation* was assessed with the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P) reflecting participants’ participation in daily life, divided over three subscales: frequencies, restrictions and satisfaction. The scores range from 0 to 100 for each subscale, with higher scores indicating better participation (higher frequency, fewer restrictions and higher satisfaction) [27]. We categorized differences into: improvement (increase of ≥ 5 points), no changes (change score between -5 to +5), and deterioration (decrease of ≥ 5) [28,29].
5. *Health-related quality of life (HRQoL)* was assessed with the EQ visual analogue scale (VAS), providing a quantitative measure of the participants’ perception of their health. The score of the EQ-VAS ranges from 0 to 100, with higher scores indicating higher HRQoL [30]. A score of <70 points indicates poor HRQoL. We categorized differences into: improvement (increase of ≥ 8 points), no changes (change score between -8 to +8), and deterioration (decrease of ≥ 8) [31].

Data analysis

Descriptive statistics were used to describe the characteristics of the 30 participants selected for this study and their patient-reported outcomes, using numbers and proportions for categorical variables and means with range for continuous variables.

Qualitative methods

Data collection

A semi-structured interview guide was developed based on literature and several aspects of the quantitative patient-reported outcomes, addressing the topics of physical functioning, fatigue, psychological complaints, participation, and previous medical history. Furthermore, participants were interviewed on their experiences with received treatment by one or multiple primary care allied health professionals. All interviews were conducted between January and April 2022. The interviews were conducted using Microsoft Teams ($n=28$) or telephone ($n=2$). Participants gave their consent for audiotaping the interviews and each interview lasted on average 46 (range 34–63) minutes.

Data analysis

All audiotaped interviews were transcribed verbatim and thematic analysis [32] was used to describe patterns in participants’ individual experiences. Subthemes and overarching themes were identified after closely reading and coding the transcribed interviews. All themes were compiled into a mind map to identify the essence of each theme, search for relations across cases, look for deviant cases, and analyse variation within and between cases. Atlas.ti 9.0 software was used throughout the coding process to organise the codes, identify initial categories, and maintain a coding framework. The interviews were coded by five research staff members and discussed within the full team to reach consensus.

Combining quantitative and qualitative data

The purpose of pairing quantitative and qualitative components of this study was to 1) integrate both methods to provide a better understanding of the experiences of patients who received primary care allied healthcare to support their recovery from COVID-19 related to quantitative measurements, and to 2) generate a more complete comprehensive knowledge on the potential factors that underlie the effects of allied healthcare by complementarity, strengthening and consistency of results. A mixed methods study is, therefore, a good approach to obtain in-depth information and knowledge of the problem [17,18]. In addition, this approach assists in increasing the credibility of the findings through combination of quantitative and qualitative results, the methodological triangulation [33].

We combined quantitative and qualitative data on an individual level to gain insight into differences and similarities between them. Combined, these datasets enable a more complete and comprehensive evaluation of the changes among participants. To combine and interpret the quantitative and qualitative data, we categorised data on the patient-reported outcomes into improvement, no changes, or deterioration, as described before. We aimed to make contextual statements (i.e. within our group of participants) reflecting individual experiences related to the objective outcome measures based on the quantitative results, because we could not make generalising statements about the entire cohort [34]. However, the 30 participants selected for this mixed methods study reflected the overall cohort based on participant characteristics and patient-reported outcomes, as appeared after comparing the scores of the 30 participants included in this study and the 1,451 participants of the total cohort.

To identify characteristics that could explain experiences of participants, relevant qualitative (sub)themes and quantitative data were integrated. Starting from the quantitative outcome measurements, we integrated the qualitative (sub)themes related to these outcomes with the quantitative analysis. As new ideas for potential characteristics derived from the qualitative (sub) themes were found, we conducted a second quantitative data analysis. For example, differences in experiences between participants at home and participants in hospital were not included in the initial analyses but were added after discussing the qualitative results. Finally, we addressed the integrated results in the discussion paragraph of this manuscript.

Results

Participant characteristics

Characteristics of the 30 participants are included in Table 1. Mean age was 52 (range 62–73) years and 20 participants (67%) were female. Seventeen participants (57%) had experienced mild to moderate severity of symptoms during the infection period. Twelve participants (40%) had been hospitalised for COVID-19, two of whom had been admitted to an intensive care unit. Hospitalisation duration ranged from 1 to 18 days. Twenty-six participants (87%) lived with a partner and/or children and four participants lived alone. More than half of the participants had a high educational level. Mean BMI was 29 kg/m² (range 18–43) and 20 participants (71%) were classified as being overweight or obese (BMI ≥ 25 kg/m²). One third of the participants had two or more comorbidities such as asthma, cancer, mental problems, overweight, or hypertension. Most participants received treatment by more than one primary care allied health professional (63%).

Quantitative results

Table 2 depicts the patient-reported outcomes at the start of treatment by one or multiple primary allied health professionals, and after 6 months of follow-up.

Physical functioning

Based on the PROMIS-PF-10b scores for physical functioning, 90% of the participants reported to be more than 60% physically impaired, limited or restricted at the start of primary allied health treatment, which decreased to 30% at 6 months.

Fatigue

At the start of treatment, 97% of participants reported severe fatigue and after 6 months 83% still reported severe fatigue. Home participants reported severe fatigue more often (89%) than hospital participants (75%) at 6 months after starting primary allied health treatment.

Psychological well-being

Most participants scored less than 7 points on the HADS anxiety and depression scores both at the start of treatment and 6-month follow-up. Home participants were more often indicated with possible or probable anxiety at 6 months after the start of primary allied health treatment than hospital participants. Of the 18 home participants, 33% had possible or probable anxiety and 22% possible or probable depression; versus 8% of the hospital participants who had a possible or probable anxiety and depression.

Participation

All scores on participation scales were improved at 6 months from the start of treatment. Home participants scored worse on the restrictions and satisfaction scale of the USER-P compared to

hospital participants, both at the start of treatment and after 6 months. Scores on the frequencies scale were comparable between both groups.

Health-related quality of life

Mean score on the EQ-VAS was 52 (range 20–80) at the start of treatment; 83% of the participants reported a poor HRQoL. At 6 months, the mean score was 71 (range 30–100) with 33% reporting a poor HRQoL.

Qualitative results

Several themes and associated sub-themes were derived from the analysis of the interviews. Below, only the 5 themes with associated subthemes focusing on the quantitative outcomes (physical functioning, mental functioning, comorbidities, participation and primary allied healthcare regulation) are further elaborated.

Physical functioning

All participants reported experiencing many physical complaints during the acute phase of COVID-19. At the time of the interviews only a few indicated that they hardly experienced any residual complaints. The vast majority had complaints of decreased walking ability, inadequate fitness level, decreased muscle strength, neuropathy, shortness of breath on exertion, or energy running out too quickly:

General Practitioner (GP) sent me to the emergency room where it turned out to be a pulmonary embolism, but the hospital was full. So sent to another hospital and after three days on oxygen sent back home to make room, couldn't even walk 30m because saturation dropped to 70. After eating an apple I was completely out of breath, after showering my saturation was 83. After 7 months, I could walk about 300 m. Now after 15 months no more physiotherapy, I row every day, am on the exercise bike every day. I still run out of energy very

Table 2. Patient-reported outcomes at start of treatment by one or more primary allied health professionals, and after 6 months of follow-up.

Patient-reported outcomes	Total group (n = 30)		Home participants (n = 18)		Hospital participants (n = 12)	
	Start of treatment	Six months after start of treatment	Start of treatment	Six months after start of treatment	Start of treatment	Six months after start of treatment
Physical functioning						
PROMIS-PF T-score, mean (range)	35.9 (28.2–42.3)	43.8 (28.2–61.3)	36.9 (28.2–41.5)	43.9 (33.5–61.3)	34.5 (30.3–42.3)	43.6 (28.2–55.0)
≥60% limited or restricted, n (%)	27 (90)	9 (30)	16 (89)	5 (28)	11 (92)	4 (33)
Fatigue						
FSS mean score, mean (range)	5.7 (2.1–7)	4.7 (1.6–6.8)	5.9 (2.1–7.0)	5.0 (2.4–6.8)	5.5 (4.3–6.7)	4.3 (1.6–5.9)
Severe fatigue (≥4 points), n (%)	29 (97)	25 (83)	17 (94)	16 (89)	12 (100)	9 (75)
Psychological well-being						
HADS anxiety score, mean (range)	7.4 (0–18)	5.1 (0–20)	8.7 (2–18)	6.2 (1–20)	5.5 (0–17)	3.5 (0–12)
No anxiety (≤7 points), n (%)	18 (60)	23 (77)	10 (55)	12 (67)	8 (67)	11 (92)
Possible anxiety (8–10)	4 (13)	2 (7)	3 (17)	2 (11)	1 (8)	0
Probable anxiety (≥11)	8 (27)	6 (16)	5 (28)	4 (22)	3 (25)	1 (8)
HADS depression score, mean (range)	7.8 (0–18)	4.9 (0–20)	8.8 (3–18)	5.9 (2–20)	6.3 (0–17)	3.5 (0–11)
No depression (≤7 points), n (%)	15 (50)	25 (83)	8 (44)	14 (78)	7 (58)	11 (92)
Possible depression (8–10)	7 (23)	3 (10)	5 (28)	3 (17)	2 (17)	0
Probable depression (≥11)	8 (27)	2 (7)	5 (28)	1 (5)	3 (25)	1 (8)
Participation, mean (range)						
USER-P frequencies scale	24 (6–38)	30 (8–51)	25 (6–38)	30 (10–51)	23 (7–36)	30 (8–44)
USER-P restrictions scale	61 (30–88)	80 (45–100)	57 (30–76)	77 (45–100)	67 (42–88)	83 (48–100)
USER-P satisfaction scale	45 (23–80)	62 (28–85)	42 (23–80)	58 (28–85)	50 (31–70)	67 (45–83)
Health-related quality of life						
EQ-VAS, mean (range)	52 (20–80)	71 (30–100)	51 (30–80)	69 (30–100)	52 (20–75)	75 (60–100)
Poor HRQoL (<70 points), n (%)	25 (83)	12 (40)	15 (83)	7 (39)	10 (83)	4 (33)

Abbreviations: USER-P = Utrecht Scale for Evaluation of Rehabilitation Participation; EQ-VAS = EuroQol Visual Analogue Scale; FSS = Fatigue Severity Scale; PROMIS = Patient-Reported Outcomes Measurement Information System; HADS = Hospital Anxiety and Depression Scale; SD = standard deviation.

*Data were not fully available for all participants: the n denotes the number of participants with available data.

quickly, my memory is still problematic, and I still can't play the fast notes on my wind instrument. (male, 57 year, hospital participant, 15 months after COVID-19, extreme fatigue, 25% declared unfit for work)

Particularly home participants also reported persistent fatigue, difficulties with balance, re-infection and then pneumonia, reduced physical and cognitive capacity and headache. One of the home participants was diagnosed with myocarditis with cardiac consequences.

Fatigue

Almost all participants experienced fatigue, with the smallest half reporting extreme fatigue, slightly more often home participants than hospital participants:

... I'm going to test just to be sure, then miraculously I turned out to be positive. Then I spent a week in bed, too tired to hold my mobile phone and well, when I was allowed out of quarantine, I uuuuh got on my feet, but I kept having symptoms. Yes, I stayed tired, I couldn't move. I got all discouraged by that. (female, 73yr, home participant)

Some hospital participants who had to make room in the hospital quickly, because hospitals were overcrowded with severe COVID-19 patients, also experienced extreme fatigue:

A few of the home participants indicated that fatigue diminished over time. Four other participants reported fatigue even before COVID-19 infection because of going through cancer treatment (twice), a muscle disease and non-congenital brain injury resulting from a car accident.

Mental functioning

Mental complaints frequently mentioned by most participants were loss of concentration, overstimulation, difficult pace and pressure regulation. Home participants additionally indicated stimulus processing being difficult enough in daily life, let alone work and effort intolerance:

... when I do absolutely nothing on a day then it kind of buzzes in the background and I can sort of switch it off. But if you become more active, the stimuli around you, the thinking, and yes, the fatigue also still predominate. And well, things are going a bit better now, cognitively speaking, I am better able to remember things. But when you really need to concentrate or have to follow different conversations in a group of four people, or concentrate for longer periods at a time, that is all still difficult, and the complaints increase. If that happens regularly, then at some point I just sort of seize up in my head and then nothing will come out, I sort of shut down ... (female, 26yr, home participant, no comorbidities)

Psychological well-being

Many symptoms were reported by both hospital and home participants in cognitive, mental and physical areas. These complaints were reported as severe by the majority of hospital participants and mild/moderate by home participants. At the same time, home participants reported more complaints, experienced a longer period of illness and had a slower return to work than hospital participants.

Home participants experienced many negative emotions: gloom, not wanting this anymore, fear (of infecting others, of death):

At first I thought, I am going to die. The fever was so high. [...] I thought, I'm not going to make it. You feel so awful. And I thought yes well, that's it, it's over. And then you get into this state of mind of a kind of resignation, as if you are between heaven and earth or something. At first you are very scared. Afraid like, I'm going to die, and then you go into that state of, alright, if that's the case, then that's okay too. (male, 56yr, home participant, single, no comorbidities)

A few home participants had more positive reactions:

...What you are obviously very worried about is that it takes so long. I was also sick for a long time plus there was this fog in my head. I told the company doctor it's as if I am looking at the world through a wet glass wall, as if you're really not quite there. And that lasted quite a while and I didn't like that. You think like, I hope this will pass. But not that I was anxious or depressed, it wasn't that bad, but you think, o dear I do hope it's going to get better. (woman, 59yr, with family, non-congenital brain injury)

Well no, of course I thought about that happening to me, but I am not afraid of it, no. (male, 58yr, with family, no comorbidities)

Hospital participants were fairly positive in their recovery despite a vast array of symptoms.

So much has happened in such a short period. At work you have seen people die. And then you are carried off yourself. My husband wasn't allowed to come with me. Well, then you do think like, will I be coming home again? It really shakes you badly psychologically speaking. The lung specialist says: "Well, in our book you are all better again, yes you are going home. And that's when the real misery starts. Look, when you're in a hospital, you don't realise how serious things actually are or what it is like. It's when you get home that you realise what has happened." (female, 46yr, with family, Diabetes mellitus)

Although, hospital participants also experienced a lot of anxiety:

I think it was worse for my wife than for me. Although the second night in hospital became a very emotional one. I felt so terribly sick and had such difficulty breathing. Yes ... and all the stories you've already heard by then. Yes, I was scared then. I was all alone in a room, which was a very grim experience. For a long time after I came out of hospital, it was very difficult to talk about it. It made me very emotional. It really hit home, tears ran down my cheeks at the slightest thing. (male, 62yr, with family, no comorbidities)

Developing and maintaining energy balance was experienced as very difficult; many participants indicated searching very hard to find their ways, which was often accompanied by negative emotions, such as gloom.

Participation

Participation was based on participants' experiences of to what extent they felt recovered, usually related to work. Almost all participants were gainfully employed before COVID-19 but only a few returned to work with the same number of hours as before COVID-19 (four participants), although some of them did not feel totally recovered:

What really still bothers me is my energy level. And the fact that I still don't sleep very well. I can't sleep through the night. I will sleep for about three hours and then watch time ticking by quite a few times... I just can't recharge the battery enough at night. But I am working full-time again, there is that. Although by the end of the week I am much more tired than at the start of the week. I notice that that is much worse than before covid. And especially with regard to sleeping. (female, 51 yr, home participant, back at work full-time as a receptionist/telephonist after 10 months)

A single retired participant reported full recovery, but he too experienced remaining complaints:

Yes, at the moment I'm actually doing well. What I do notice is, we like to go for walks but as soon as it requires more of a physical effort, for instance having to climb while walking, or when I am helping my son with odd jobs, I notice that I don't have enough air. It has taken a toll on the condition of my lungs. (female, 68yr, hospital participant 9 days on ICU, retired nurse, experiences recovery after 7 months)

Most participants were still in a very slow accrual of work hours or started working less because they could not cope with a higher load, especially due to fatigue. The very slow accrual meant that each time after adding some hours to the number of working hours, hours remained stable for a longer period of time before the next step could be taken (plateau wise accrual). These participants reported partial recovery at the time of the interview (mean 12.4 months after COVID-19 infection was established), ranging from very minimal to about 75%. A few participants reported still not feeling recovered at all or not having returned to work:

I am still not working, I just can't. Fortunately I have an understanding company doctor and a sympathetic boss, but processing stimuli is a real burden and I can't even manage living my daily life the way I want to, without having to work. So yes, I'm not ready to take the step towards working and it will be a while yet. And well, I am now approaching that one year of being ill and recovery care is only for one year, so I am afraid I will have no choice but to stop that, because my income will be down to 70 per cent and if you have to pay for it yourself, it is just too expensive. (female, 26yr, home participant, 12 months after Covid-19 infection)

In the small group of participants who reported full recovery earlier than the interview dates, the recovery period took 3 to 10 months.

Comorbidities

In both groups, some participants indicated that diseases in their clinical history affected their recovery from COVID-19:

Well look because of the chemo I already have, I've also been declared unfit for work. Yes, fatigue has just been part of my life for twenty years. And yes, sometimes you're too tired to you're not tired enough to sleep, but too tired to get up. So yes, I'm familiar with that and symptoms go away more slowly when you have chemotherapy in your history. (male, 51 yr, with family, cancer, HIV, hospital participant)

Participants could not always distinguish between COVID-19 and other diseases:

I was in a car accident recently. And ehm, that left me with brain damage, so I went to an occupational therapist to organise my day in such a way that it would give me the least amount of problems. With covid that was really annoying, because with covid added to the mix, it's actually too complicated for me to distinguish between what is covid related and what is because of my brain injury, because that already made me tired much faster, sensory overload and things like that. So even before COVID I had to be careful with visual stimuli and auditory stimuli throughout the day. (female, 59 yr, with family, non-congenital brain injury, home participant)

Valuation of the primary care allied healthcare regulation

Most participants were very satisfied with the received primary care allied healthcare although a few experienced the regulation as hindering. Some participants felt that the allied health care professionals slowed down too much, for example by slowly increasing training intensity, which made participants feel limited in their development. Some participants indicated that primary care allied health professionals did not yet seem to have enough knowledge on persistent complaints after COVID-19, so complaints remained as treatment was not properly adapted to this new disease. According to participants, company doctors sometimes indicated that treatment was too strenuous. And in hindsight, occasional psychological help proved indispensable to address the situation. Some participants experienced that they needed longer primary care allied healthcare than was reimbursed because of persistent severe complaints, or because delay in start of treatment, either on the side of participants or on the side of health

care providers, leaving insufficient time within the primary care allied healthcare regulation.

Delay Sometimes treatment by a primary care allied health professional was delayed because participants waited to seek help themselves:

Last year at the end of January, I got COVID through work. And then I stayed home for 14 days to recuperate. And, well, then I went back to work. Because I thought I was okay again. But I obviously wasn't. The symptoms remained, and the longer it went on, the worse they became. So then I had a day off, and I'd do nothing and rest so I could work again the next day. Until I really couldn't go on anymore and things got worse and worse with lots of headaches, dizziness, shortness of breath. My days off were no longer enough to compensate for it. So then I called in sick in June. By then I had so many symptoms that I was really unable to do anything at all. (female, 54 yr, with family, home participant, working in nursing home)

Some participants experienced delay caused by their health care providers:

I called my GP after four and a half weeks ... gosh I've had COVID. I still have a super bad headache every day and painkillers I have don't really help enough, help. Ehm, that GP said at that point, well you've been taking paracetamol for 4 weeks now. A side effect of paracetamol is a headache, so stop that and just sick it out for a while longer. (female, 26 y, with family, home participant)

Contribution to recovery All participants were treated by one or more primary care allied healthcare professionals. Based on the interviews, more primary care allied healthcare professionals were regularly involved than was reported in the quantitative part of the study. Among the home respondents, the physiotherapist was most frequently mentioned as a practitioner and exercise therapist the least. Occupational therapists were much less frequently involved in treatment and were sometimes involved only late in treatment because of their waiting list. Among hospital respondents, one or more allied healthcare professionals were already involved during hospital stay, especially physiotherapists and dietitians. Again, after discharge the physiotherapist was mentioned most often and the exercise therapist least. Hospital respondents indicated that, at the physiotherapist, almost all possible types of treatment (such as exercise, instruction how to handle complaints at home, listening ear) were utilised and perceived as necessary. Both home and hospital respondents reported that speech language therapists were hardly ever consulted, as were exercise therapists.

Tender loving care and sympathetic ear, but also learning to manage limits, support and acceptance to build up in small steps were perceived by participants as contributing most to their recovery.

Helped me greatly: Without them I wouldn't have made it ... I was so stuck. Such warm-hearted support. (female, 35 yr, with family, multidisciplinary allied health treatment, home participant)

It's been really good [6 months of recovery care] ehm without it I probably wouldn't have come this far. Because they also test you every time, you do intermediate tests. That I just walked around our house and was able to go a bit further each time. If this hadn't been there, I wouldn't have known how to go about it; they, occupational and physio, really pulled me through. (female, 46 yr, with family, multidisciplinary allied health treatment, home participant)

But some were less satisfied:

Well, satisfied. Look, I am not complaining about the care, because I completely understand; it's a new disease. They don't know. But if, ... well to say that the care was helpful for me, no ... and barely. I shouldn't exaggerate, barely, they did help in the sense that they were

able to reassure me that there is nothing seriously wrong. So ... The cardiologist, the neurologist, the ehM dietitian, they have managed to reassure me. (female, 54yr, with family, multidisciplinary allied health treatment, home participant)

Satisfaction with primary allied health professionals, particularly among home respondents, was fair to good. A few participants from both groups indicated that the schedules presented by occupational therapists did not match their arrangement of their own daily life:

But in the first meetings with the occupational therapist, out came the lists, like start keeping track of what you do every 15 minutes. Well instead of giving me peace of mind, it added pressure. Now you have to start writing down what you do every fifteen minutes. Well, if you know that what I do is have meetings, which take three quarters of an hour, an hour. And then on to the next meeting. Well, if you have to keep track of what you are doing every fifteen minutes. That's more of a burden than a help. And maybe I was too hasty or too down-to-earth for that. I don't know, it just didn't feel right to do that. I didn't feel like it would help me. (male, 62yr, with partner, multidisciplinary allied health treatment, hospital participant)

Respondents indicated that sometimes too many health care professionals were involved in their care, making their week feel very full and overloaded; they sometimes made their own decisions to cut down on visits to allied health professionals or to even terminate treatment earlier.

Discussion

In this mixed-methods study, we aimed to describe changes in recovery trajectories of people recovering from COVID-19 who were treated by one or more primary care allied health professionals and how they dealt with persistent complaints.

Combined results and interpretation

Physical functioning

For physical functioning, the quantitative data showed that 25 participants (83%) improved at 6 months after starting primary allied healthcare. However, they had not fully recovered, as according to the interviews, most participants still had residual physical problems at the time of the interview. This finding was confirmed by the quantitative data showing that most participants still reported moderate to severe physical problems at 6 months follow-up. Most participants experienced that their residual physical problems affected their participation.

Our results are in line with previous studies showing that a large group of people with persistent complaints after COVID-19 estimated their physical capacity to be lower compared to pre-COVID, up to more than a year after infection [10,35], especially due to persistent fatigue [36].

Fatigue

We found that most participants (21/30) improved on fatigue according to the FSS score, but contrastingly, only a few interviewed participants reported that fatigue diminished over time. Despite improvements, most participants still reported many symptoms of fatigue, and both quantitative and qualitative results showed that participants were less tired but still severely fatigued. The indicated degree of fatigue in the interviews ranged from tired to extremely fatigued, even at on average 12 months after infection. Participants reported multiple factors contributing to

the frequently reported severe fatigue: a delay in start of treatment by a primary care provider because participants either waited to seek help on their own or experienced delays by their caregivers, or too early discharge from the hospital.

Previous studies have shown that fatigue is the most prevalent persistent complaint in people recovering from COVID-19, irrespective of disease severity. Consistent with literature, we found that fatigue does not resolve over time in many participants, even if they received healthcare [1,37]. It has also been shown that persistent fatigue can lead to reduced physical activity, participation and health-related quality of life, among other things [38].

Psychological well-being/mental functioning

Hospital participants were more likely to report severe mental and cognitive complaints, although home participants reported more diverse complaints and these complaints persisted longer. This could possibly be related to the fact that home participants experienced more delay and responded less quickly to complaints. In contrast to the other patient-reported outcomes, most participants reported no changes in anxiety and depression at 6 months from the start of primary allied healthcare. Nevertheless, these participants did improve on HRQoL, physical functioning, and fatigue.

Markedly, more participants reported negative emotions in the interviews compared to the quantitative data derived from the HADS, in which the majority scored less than 7 points and were indicated with no depression or anxiety. Anxiety lies in many areas that participants may not include when completing the HADS, for example: fear of infecting others, fear of re-infection, fear that symptoms will remain, and fear that symptoms will worsen underlying suffering. These findings are comparable with previous studies which have shown that alternating and uncertain recovery trajectories often caused feelings of increased anxiety [3–5]. For this outcome domain, the qualitative data not only complemented the quantitative data, the results from the interviews even provided additional insights into participants' perceptions.

Most participants in this study had a partner or family. We found that singles, only 3 in the sample and all home participants, reported high anxiety in the interviews and experienced little support. The lack of understanding is important in the relationship between people with persistent complaints after COVID-19 and their relatives, healthcare professionals, and employers. Previous studies have shown that people with persistent complaints after COVID-19 often feel misunderstood [9,10,12]. On the other hand, family and friends can play an important role as informal caregivers by supporting in self-care activities (e.g. grocery shopping and cooking) and providing emotional support [9,10].

Participation

Participation was described as participants' experiences of to what extent they felt recovered, usually related to work. Most participants (21/30) had not yet fully returned to work at the time of the interview, of whom three were still not working at all and 17 resumed working partially (25–85%). This is comparable to the USER-P scales on which most participants improved, but they did not yet score optimally, especially home participants reported to be more restricted and less satisfied on participation.

Our findings are in line with previous studies showing that people with persistent complaints after COVID-19 are often unable to return to work at their previous level (e.g. they had to adapt by reduced hours or different roles), or are even unable to work at all [9,13,36]. Especially persistent fatigue and mental or cognitive complaints were commonly described as having a major impact on returning to work [7,9].

Primary care allied healthcare regulation

Hospital participants often had already been treated in the hospital by an allied health professional, mainly a physiotherapist or dietitian, and this care was continued in primary care after discharge. In contrast, home participants often started late with primary care allied healthcare, which could explain that home participants generally reported more persistent symptoms and a longer recovery. Some participants experienced delay in starting treatment with primary allied health professionals because they wanted to work on their own recovery first or because of late referral by their GP. This left participants with insufficient time to complete a full recovery program within the timeframe allotted by the reimbursement regulation. We found that most participants were satisfied with the received primary care allied healthcare. Nevertheless, some participants indicated that primary care providers did not yet seem to have enough knowledge about persistent symptoms after COVID-19. Previous studies have shown that experiences with medical care have varied from well-meaning to inconclusive and disbelief [7]. However, even when healthcare professionals were unable to offer appropriate care, it was still important for people with persistent complaints after COVID-19 to feel heard [7,9]. In our study, the loving treatment and warm-hearted support of primary allied health professionals was perceived as contributing most to participants' recovery.

Strengths and limitations

The major strength of this study is the mixed-methods design. The combined results provide more insight into participants' experiences about their recovery from COVID-19. We performed quantitative analyses on a representative prospective dataset which we complemented with interview data. We worked sequentially, as we started with the quantitative and qualitative analyses, which were followed by another quantitative analysis. In this way, exchange of information between the two methods was possible. Based on the results of the qualitative study, which showed that home participants experienced more persistent symptoms than hospital participants, the quantitative data were re-analysed. This additional quantitative analysis confirmed the qualitative results. Unfortunately, we were not able to distinguish between participants admitted to the nursing ward or ICU, as only two participants were admitted to the ICU for COVID-19. From the quantitative study, we had no available pre-COVID data for our population, making it difficult to draw conclusions about the impact of pre-existing conditions versus problems in daily activities and participation due to participants' persistent complaints after COVID-19. The addition of the data from the interviews did allow us to make this connection.

For the interpretation of the results, it is important to consider that the baseline measurement in this study was taken at the start of the treatment by one or multiple primary care allied health professionals. It is possible that a participant had already experienced symptoms for some time and only consulted an allied health professional at a later stage. We know from the interviews that participants were included in the study on average 3 months after infection.

We selected the 30 participants from the quantitative study by purposive sampling [19], based on characteristics and patient-reported outcomes. The participants selected for the qualitative study were comparable on participant characteristics and patient-reported outcomes with the total cohort, as appeared after comparing the scores. Therefore, we assume our study population reflected the overall cohort. Our population most likely had the Wuhan or Alpha variant of COVID-19, based on the infection period [39]. Different variants may cause different symptoms [40] and the recovery trajectories of people infected with other variants may differ from our population.

Conclusion

The unique combination of quantitative and qualitative data has provided in-depth insights into the experiences of people recovering from COVID-19 and how they dealt with persistent complaints. Even though improvements were reported on almost all outcome measures, most participants experienced persistent problems (e.g. they were less tired, but still extremely fatigued). Despite these persistent problems we found a better handling of symptoms in our participants. An important result of this mixed-methods study is that home participants reported more persistent symptoms and a longer recovery than hospital participants. Tender loving care, a listening ear provided by the primary care allied health professionals, but also learning to manage limits, and support and acceptance to build up in small steps were perceived as contributing most to participants' recovery. Many participants reported being better able to cope with persistent complaints because they had decreased substantially in their intensity.

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Transparency statement

The authors affirm that this manuscript is at honest, accurate, and transparent account of study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

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Data availability statement

The data sets generated and/or analysed during this study are available from the corresponding author on reasonable request.

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