Supplementary Material

Recovery from COVID-19: a sprint or marathon?

6 month follow-up of long COVID-19 support group members

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Results

Patients with suspected COVID-19 diagnosis

Seven hundred and sixty-six patients who completed both surveys were presumed to have had COVID-19. They did not have a formal COVID-19 testing at the time of the presumed infection. Patients were mostly middle-aged women with a normal body mass index. The vast majority of the patients reported a moderate to good health status before infection (99.2%) (Supplementary Table 4).

Number of Symptoms

During the COVID-related infection a median of 14 (11-18) symptoms was reported, which was significantly lower 3 and 6 months later: 7 (4-9) and 6 (3-9), respectively (p<0.001, Supplementary Table 3). At all three time points, fatigue was the most prevalent symptom (Supplementary Figure 3).

The proportion of non-symptomatic patients increased between 3 and 6 months follow-up, from 0.5 % to 4.0% (p<0.001). After 6 months, 305 patients (40%) reported 1 to 5 symptoms, 314 patients (41%) reported 6 to 10 symptoms, and 116 patients (15%) reported more than 10 symptoms (Supplementary Figure 4).

Work productivity

The majority of patients (83.1%) reported to have a job before the infection. The mean proportion of work time missed in the previous week due to ill health (absenteeism) and impairment while working (presenteeism) reduced from 61% to 48% and from 65% to 57%, respectively (both p<0.001; Supplementary Table 4). In addition, average work productivity loss reduced from 82% to 74%, resulting in an overall working impairment of 73% and 62% after 3 and 6 months, respectively (both p<0.001; Supplementary Table 4).

Self-reported health, functional status, and quality of life

Pre-infection, 85.2% of the patients had a good self-reported health-status. After 3 months follow-up, only 4.3% of the patients rated their health as 'good', which significantly increased up to 17.0% after 6 months follow-up (p<0.001). Consequently, 83.0% of the patients still reported a moderate-to-poor self-reported health after 6 months (Supplementary Figure 5a).

Self-reported functional status did not improve from 3 to 6 months follow-up, however, the proportion of patients reporting to have currently no limitations in everyday life without infection-related symptoms significantly increased from 0.9 to 5.9% (p<0.001; Supplementary Table 4, Supplementary Figure 5c).

The mean EQ-5D index and the EQ-VAS improved significantly from 0.621 (0.184) to 0.689 (0.171) and 46 (19) to 54 (19) points, respectively (p<0.001; Supplementary Table 4). Compared to age/gender-matched reference values (1), also the proportion of patients who had an EQ-5D index that was below the fifth percentile significantly reduced from 39.4 to 28.2% (p<0.001; Supplementary Table 4). Still, 64% of the patients had moderate to extreme problems with daily activities after 6 months, and 54% of the patients experienced moderate to extreme pain or discomfort (Supplementary Figure 5d).

Received care

The proportion of patients receiving physiotherapy or rehabilitation between 3 to 6 months of follow up was significantly higher compared to the period from the infection to 3 months of follow-up (57.2% versus 24.3% and 4.4 versus 1.3%, respectively, p<0.05; Supplementary Table 4). The dependency on partner or family for personal care significantly decreased from 3 to 6 months follow-up (from 37.7% to 18.4% and from 12.1% to 4.2%, respectively, p<0.05) , though the proportion of patients needing help from their partner of family was still significantly higher compared to before the infection (18.4% versus 4.8% and 4.2% versus 1.2%, respectively; p<0.05).

References

1.   Grochtdreis T, Dams J, Konig HH, Konnopka A. Health-related quality of life measured with the EQ-5D-5L: estimation of normative index values based on a representative German population sample and value set. Eur J Health Econ. 2019;20(6):933-44.

Supplementary Table 1 Patient characteristics of responders and non-responders to the second survey

	Responders 2nd survey (n=1005)	Non-responders 2nd survey (n=551)
Women, n (%)	850 (84.6)	473 (85.8)
Age, years (median, interquartile range)	48.0 (40.0-54.5)	44.0 (37.0 – 52.0)*
BMI, kg/m² (median, interquartile range)	25.1 (22.5-28.7)	25.1 (22.5 – 28.7)
Married/living with partner, n (%)	716 (71.2)	394 (71.5)
Pre-existing comorbidities, n (%)		
None	617 (61.4)	341 (61.9)
1	258 (25.7)	142 (25.8)
≥2	130 (12.9)	68 (12.3)
Place of COVID-19 diagnosis and treatment, n (%)		*
Hospitalized, test-based diagnosis	62 (6.2)	18 (3.3)
Non-hospitalized, test-based diagnosis	177 (17.6)	86 (15.6)
Suspected COVID-19	766 (76.2)	447 (81.1)
Time between symptom onset (T0) and completion first questionnaire (T1), weeks (mean (SD))	11.3 (2.2)	11.4 (2.4)
Health status before infection, n (%)		
Good	861 (85.7)	470 (85.3)
Moderate	135 (13.4)	80 (14.5)
Poor	9 (0.9)	1 (0.2)
Self-reported poor health, %		
Before	0.9	0.2
T1	32.3†	29.8†
Number of symptoms, n (median, interquartile range)		
T0	14 (11-18)	14 (10-18)
T1	7 (4-9) †	6 (4-10) †

*p<0.05 vs. responders 2nd round; †p>0.05 vs T0

Supplementary Table 2 Patient characteristics of hospitalized and non-hospitalized patients with confirmed COVID-19 diagnosis

	Hospitalized patients (n=62)	Non-hospitalized patients (n=177)
Women, n (%)	39 (62.9)	159 (89.8)†
Age, years (median, interquartile range)	53.0 (47.8-60.0)	48.0 (37.5-54.5)†
BMI, kg/m²(median, interquartile range)	28.2 (24.8-32.6)	25.6 (23.0-29.4)†
Married/living with partner, n (%)	43 (69.4)	130 (73.4)
Pre-existing comorbidities, n (%)		†
None	28 (45.2)	114 (64.4)
1	23 (37.1)	39 (22.0)
≥2	11 (17.7)	24 (13.6)
Health status before infection, n (%)		
Good	49 (79.0)	159 (89.8)
Moderate	12 (19.4)	16 (9.0)
Poor	1 (1.6)	2 (1.1)
Time between symptom onset (T0) and completion questionnaire, weeks (mean (SD))		
First questionnaire (T1)	11.1 (2.0)	10.1 (2.4)
Second questionnaire (T2)	23.4 (2.0)	22.4 (2.4)
Number of symptoms, n (median, interquartile range)		
T0	14 (10-17)	15 (12-18)
T1	6 (4-8)*	6 (4-9)*
T2	6 (2-8)*	6 (3-8)*#
Work Productivity and Activity Index		
Percentage of work time missed due to ill health (absenteeism) (mean (SD))		
T1	81.5 (29.0)	70.4 (36.5)
T2	60.0 (36.9)#	50.0 (38.6)#
Percentage of impairment while working (presenteeism) (mean (SD))		
T1	67.8 (29.0)	65.8 (25.2)
T2	59.7 (23.3)#	59.7 (24.3)#
Overall work impairment due to health (work productivity), % (mean (SD))		
T1	93.0 (16.5)	88.2 (20.1)
T2	82.9 (26.2)#	77.3 (25.9)#
Activity impairment, % (mean (SD))		
T1	71.8 (22.9)	71.3 (21.3)
T2	57.3 (24.6)#	60.5 (22.1)#
Self-reported poor health, %		
T0	1.6	1.1
T1	25.8*	25.4*
T2	8.1*#	11.3*#
Post-COVID-19 Functional Status Scale, Grade (mean (SD))		
T1	2.3 (1.1)	2.4 (0.8)
T2	2.2(1.1)	2.2 (0.9)#
Quality of life		
EQ-5D index (mean (SD))		
T1	0.643 (0.202)	0.646 (0.173)
T2	0.710 (0.180)#	0.688 (0.159)#
EQ-5D index < P5 reference values [23], %		
T1	35.5	37.3
T2	24.2#	27.7#
Today's health status (VAS 0-100), points		
T1	49 (21)	49 (18)
T2	57 (20)#	56 (18)#

Received care		
Physiotherapy, %		
Between T0 and T1	48.4	26.0†
Between T1 and T2	61.3#	62.1#
Rehabilitation, %		
Between T0 and T1	9.7	2.3†
Between T1 and T2	12.9	11.3#
Need for help with personal care		
From partner, %		
Before	6.5	4.5
Between T0 and T1	56.5*	42.4*
Between T1 and T2	22.6#	20.9*#
From family, %		
Before	1.6	1.7
Between T0 and T1	22.6*	15.3*
Between T1 and T2	9.7*#	6.2*#

†p<0.05 vs. hospitalized patients; *p<0.05 vs. before; #p<0.05 vs. T1; P5=percentile five; VAS=visual analogue scale

Supplementary Table 3 Patient characteristics of patients receiving physiotherapy/rehabilitation and patients not receiving physiotherapy/rehabilitation

	Patients receiving physiotherapy/rehabilitation (n=155, 64.9%)	Patients not receiving physiotherapy/rehabilitation (n=84, 35.1%)
Women, n (%)	133 (85.8)	65 (77.4)
Age, years (median, interquartile range)	50.0 (40.0-56.0)	49.0 (39.0 – 57.8)*
BMI, kg/m² (median, interquartile range)	26.2 (23.7-30.7)	25.6 (23.1 – 29.3)
Married/living with partner, n (%)	113 (72.9)	60 (71.4)
Pre-existing comorbidities, n (%)		
None	93 (60.0)	49 (58.3)
1	38 (24.5)	24 (28.6)
≥2	24 (15.5)	11 (13.1)
Place of COVID-19 diagnosis and treatment, n (%)		*
Hospitalized, test-based diagnosis	41 (26.5)	21 (25.0)
Non-hospitalized, test-based diagnosis	114 (73.5)	63 (75.0)
Health status before infection, n (%)		
Good	131 (84.5)	77 (91.7)
Moderate	21 (13.5)	7 (8.3)
Poor	3 (1.9)	0 (0.0)
Number of symptoms, n (median, interquartile range)		
T0	15 (12-18)	14 (10-17)
T1	7 (5-9)†	5 (3-8)*†
T2	6 (4-9)	4 (2-7)*
Self-reported poor health, %		
Before	1.9	0.0
T1	32.3†	13.1*†
T2	13.5†	4.8*†
Work Productivity and Activity Index		
Percentage of work time missed due to ill health (absenteeism) (mean (SD))		
T1	82.0 (28.3)	56.2 (40.4)*
T2	64.8 (34.3)†	28.5 (34.4)*†
Percentage of impairment while working (presenteeism) (mean (SD))		
T1	75.0 (22.7)	55.2 (25.4)*
T2	66.1 (20.4)†	49.5 (26.0)*
Overall work impairment due to health (work productivity), % (mean (SD))		
T1	93.5 (14.7)	80.8 (24.5)*
T2	86.6 (18.9)†	62.2 (30.6)*†
Activity impairment, % (mean (SD))		
T1	77.0 (17.5)	61.2 (24.9)*
T2	64.8 (19.7)†	50.1 (25.0)*†
Post-COVID-19 Functional Status Scale		
Grade (mean (SD))		
T1	2.6 (0.7)	2.0 (0.7)*
T2	2.5 (0.8)	1.8 (1.0)*
Quality of life		
EQ-5D index (mean (SD))		
T1	0.613 (0.173)	0.706 (0.179)*
T2	0.663 (0.155)†	0.751 (0.168)†*
EQ-5D index < P5 reference values [20], %		
T1	41.3	28.6
T2	30.3†	20.2
Today's health status (VAS 0-100), points		

T1	45 (18)	57 (17)*
T2	52 (18)†	65 (17)†*
Need for help with personal care		
From partner, %		
Before	5.2	4.8
Between T0 and T1	50.3†	38.1†
Between T1 and T2	24.5†#	15.5†#
From family, %		
Before	1.9	1.2
Between T0 and T1	21.3†	9.5†*
Between T1 and T2	7.7†#	6.0

*p<0.05 vs. patients receiving physiotherapy/rehabilitation; †p>0.05 vs before/during infection; *#p<0.05 vs. T1*

Supplementary Table 4 Characteristics of patients with suspected COVID-19

	N=766
Women, n (%)	652 (85.1)
Age, years (median, interquartile range)	48.0 (40.0-54.0)
BMI, kg/m² (median, interquartile range)	24.7 (22.2-28.1)
Married/living with partner, n (%)	543 (70.9)
Pre-existing comorbidities, n (%)	
None	475 (62.0)
1	196 (25.6)
≥2	95 (12.4)
Health status before infection, n (%)	
Good	653 (85.2)
Moderate	107 (14.0)
Poor	6 (0.8)
between symptom onset (T0) and completion questionnaire, weeks (mean (SD))	
First questionnaire (T1)	11.5 (2.1)
Second questionnaire (T2)	23.8 (2.1)
Number of symptoms, n (median, interquartile range)	
T0	14 (11-18)
T1	7 (4-9)*
T2	6 (3-9)*†
Work Productivity and Activity Index	
Percentage of work time missed due to ill health (absenteeism) (mean SD))	
T1	61.4 (38.0)
T2	47.5 (39.8)*
Percentage of impairment while working (presenteeism) (mean (SD))	
T1	64.9 (25.3)
T2	57.3 (26.5)*
Overall work impairment due to health (work productivity), % (mean (SD))	
T1	82.2 (24.8)
T2	74.0 (28.8)*
Activity impairment, % (mean (SD))	
T1	72.9 (20.9)
T2	61.8 (24.0)*
Self-reported poor health, %	
Before	0.8
T1	34.5*
T2	15.1*†
Post-COVID-19 Functional Status Scale	
Grade (mean (SD))	
T1	2.6 (0.7)
T2	2.6 (0.9)
Quality of life	
EQ-5D index (mean (SD))	
T1	0.621 (0.184)
T2	0.689 (0.171)*
EQ-5D index < P5 reference values (1), %	
T1	39.4
T2	28.2*
Today's health status (VAS 0-100), points	
T1	46 (19)
T2	54 (19)*

Received care		
Physiotherapy, %		
Between T0 and T1	24.3	
Between T1 and T2	57.2*	
Rehabilitation, %		
Between T0 and T1	1.3	
Between T1 and T2	4.4*	
Need for help with personal care		
From partner, %		
Before	4.8	
Between T0 and T1	37.7*	
Between T1 and T2	18.4*†	
From family, %		
Before	1.2	
Between T0 and T1	12.1*	
Between T1 and T2	4.2*†	

*p<0.05 vs. before; †p<0.05 vs. T1

Supplementary Figure Legends

Supplementary Figure 1   **Study flow chart**

Supplementary Figure 2   **Number of symptoms during the infection and after 3 months and 6 months of follow-up patients with confirmed COVID-19 diagnosis (n=239)**

■ During infection; ■ 3 months after start symptoms; ■ 6 months after start symptoms

Supplementary Figure 3   **Prevalence of symptoms during the infection and after 3 months and 6 months of follow-up in patients with suspected COVID-19 (n=766)**

Abbreviations: temp.=temperature; BW=body weight; HR=heart rate.

■ During infection; ■ 3 months after start symptoms; ■ 6 months after start symptoms

Supplementary Figure 4   **Number of symptoms during the infection and after 3 months and 6 months of follow-up in patients with suspected COVID-19 (n=766)**

■ During infection; ■ 3 months after start symptoms; ■ 6 months after start symptoms

Supplementary Figure 5   **Self-reported health, Functional Status, and Quality of life in patients with suspected COVID-19 (n=766)**

a. Self-reported health status before the infection and after 3 months and 6 months of follow-up in patients with suspected COVID-19 (n=766)

The width of lines is proportional to the flow rate.

■ Good; ■ Moderate; ■ Poor

■ 3.4% of the patients: good → good → good; ■ 0.7% of the patients: good → good → moderate; ■ 10.8% of the patients: good → moderate → good; ■ 39.9% of the patients: good → moderate → moderate; ■ 2.9% of the patients: good →

moderate → poor; ■ 2.0% of the patients: good → poor → good; ■ 17.2% of the patients: good → poor → moderate; ■ 8.4% of the patients: good → poor → poor; ■ 0.1% of the patients: moderate → good → good; ■ 0.1% of the patients: moderate → good → moderate; ■ 0.5% of the patients: moderate → moderate → good; ■ 5.9% of the patients: moderate → moderate → moderate; ■ 0.9% of the patients: moderate → moderate → poor; ■ 0.1% of the patients: moderate → poor → good; ■ 3.7% of the patients: moderate → poor → moderate; ■ 2.6% of the patients: moderate → poor → poor; ■ 0.3% of the patients: poor → moderate → moderate; ■ 0.1% of the patients: poor → poor → moderate; ■ 0.4% of the patients: poor → poor → poor

b. Post-COVID-19 Functional Status Scale after 3 months and 6 months of follow-up in patients with suspected COVID-19 (n=766)

The width of lines is proportional to the flow rate.

Grade 0: I have no limitations in my everyday life and no pain, depression or anxiety related to the infection.

Grade 1: I have negligible limitations in my everyday life as I can perform all usual duties/activities, although I still have persistent symptoms, pain, depression or anxiety.

Grade 2: I suffer from limitations in my everyday life as I occasionally need to avoid or reduce usual duties/activities or need to spread these over time due to symptoms, pain, depression or anxiety. I am, however, able to perform all activities without any assistance.

Grade 3: I suffer from limitations in my everyday life as I am not able to perform all usual duties/activities due to symptoms, pain depression or anxiety. I am, however, able to take care of myself without any assistance.

Grade 4: I suffer from severe limitations in my everyday life: I am not able to take care of myself and therefore I am dependent on nursing care and/or assistance from another person due to symptoms, pain, depression or anxiety.

■ Grade 0; ■ Grade 1; ■ Grade 2; ■ Grade 3; ■ Grade 4

0.7% of the patients: Grade 0 → Grade 0; 0.1% of the patients: Grade 0 → Grade 1; 0.1% of the patients: Grade 0 → Grade 3; 2.2% of the patients: Grade 1 → Grade 0; 3.0% of the patients: Grade 1 → Grade 1; 1.2% of the patients: Grade 1 → Grade 2; 0.3% of the patients: Grade 1 → Grade 3; 2.1% of the patients: Grade 2 → Grade 0; 6.1% of the patients: Grade 2 → Grade 1; 14.4% of the patients: Grade 2 → Grade 2; 7.0% of the patients: Grade 2 → Grade 3; 0.1% of the patients: Grade 2 → Grade 4; 0.9% of the patients: Grade 3 → Grade 0; 3.1% of the patients: Grade 3 → Grade 1; 15.9% of the patients: Grade 3 → Grade 2; 38.3% of the patients: Grade 3 → Grade 3; 1.0% of the patients: Grade 3 → Grade 4; 0.3% of the patients: Grade 4 → Grade 2; 2.2% of the patients: Grade 4 → Grade 3; 0.9% of the patients: Grade 4 → Grade 4

c. Problems on EQ-5D-5L domains after 3 months and 6 months of follow-up in patients with suspected COVID-19 (n=766)

☐ No problems; ■ Slight; ■ Moderate; ■ Severe; ■ Extreme/unable