

Supplementary Information for:

**Following pediatric and adult IBD patients through the COVID-19 pandemic:
changes in psychosocial burden and perception of
infection risk and harm over time**

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Supplementary Figure S1

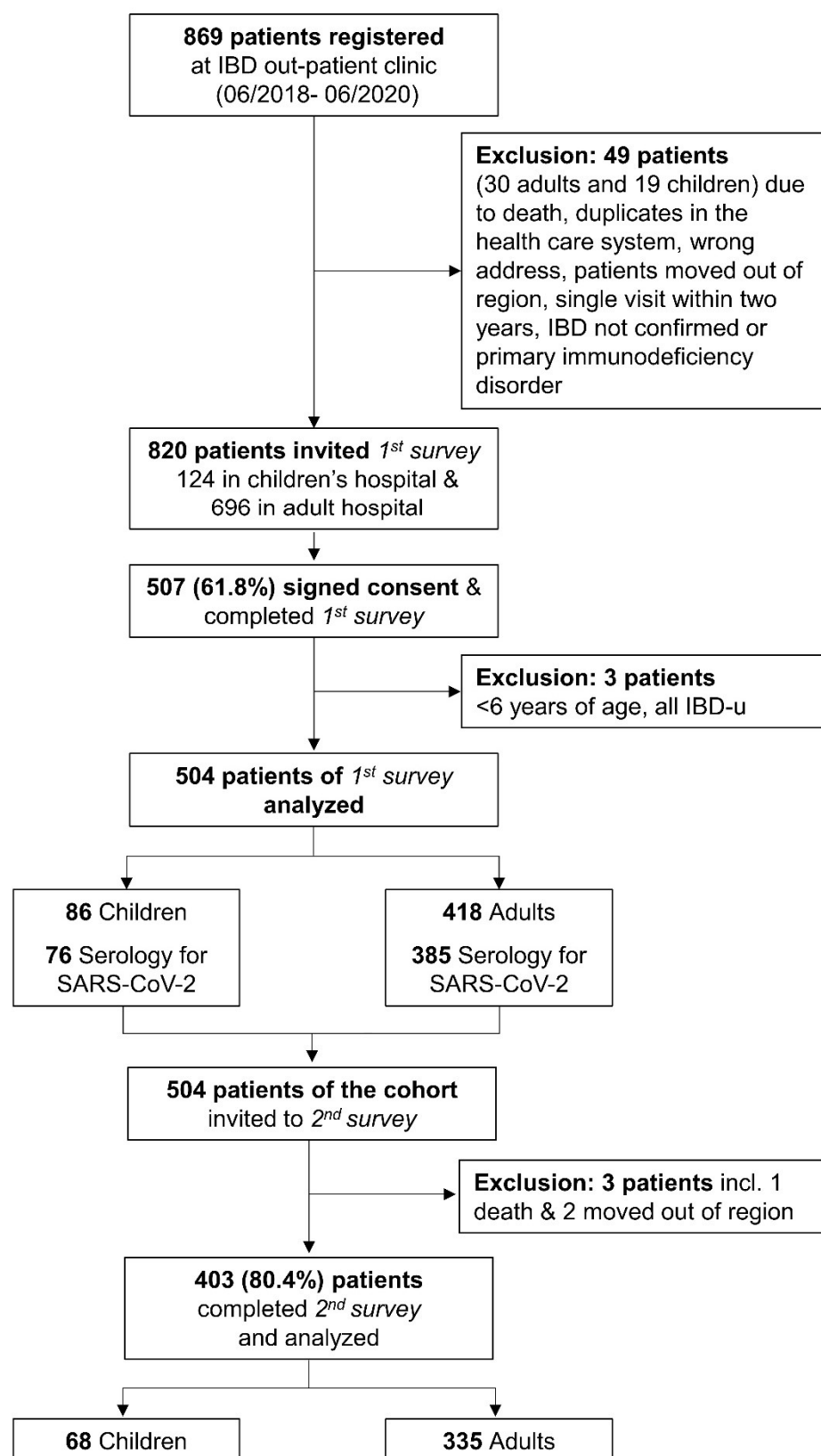


Fig. S1: Flow chart of participants in the first and second survey of the COVID-19 cohort study.

Supplementary Figure S2

I. High-risk comorbidities associated with severe COVID-19 illness: <ol style="list-style-type: none"> 1. Diabetes (type I or type II) 2. Chronic liver disease 3. Chronic lung disease 4. Chronic heart disease 5. Arterial hypertension 6. Rheumatic diseases 7. Stroke 8. Cancer 9. Renal insufficiency 10. Overweight / Obesity or BMI ≥ 30 kg/m² 11. HIV 		1 point, if one comorbidity 2 points, if two comorbidities 3 points, if ≥ 3 comorbidities
II. Transplantation (organ, hematopoietic)		+ 2 points
III. Treatment with any immunosuppressive medication including biologics, immunomodulator or steroids		+ 1 point
IV. Age >70 years		+ 1 point
SIRSCO Total Score: <ul style="list-style-type: none"> • 0 points, patient has no increased risk. • 1 point, patient has mild risk. • 2 points, patient has moderate risk. • 3-4 points, patient has severe risk • ≥ 5 points, patient has very severe risk. 		

Fig. S2: Scoring for increased risk for severe COVID-19 outcome SIRSCO index. Based on information patients reported on their currently used medications, known comorbidities, weight and height, we calculated an individual risk score for severe illness from COVID-19. Comorbidities were selected based on information provided by the Robert Koch Institute, a public health institute in Germany (www.rki.de). Chronic liver disease included autoimmune hepatitis, cholangitis (PSC) or other chronic liver disease, chronic lung disease included asthma, COPD, or other chronic lung diseases, chronic heart disease included coronary heart disease, heart insufficiency, cardiac arrhythmia or peripheral arterial disease. Other comorbidities reported by patients on skin allergy, psoriasis, allergies of the respiratory tract, autoimmune disease, other comorbidities / other chronic diseases were excluded in the consideration of high-risk comorbidities. Based on the total score, patients were stratified in 5 risk groups for severe illness from COVID-19.

Supplementary Figure S3

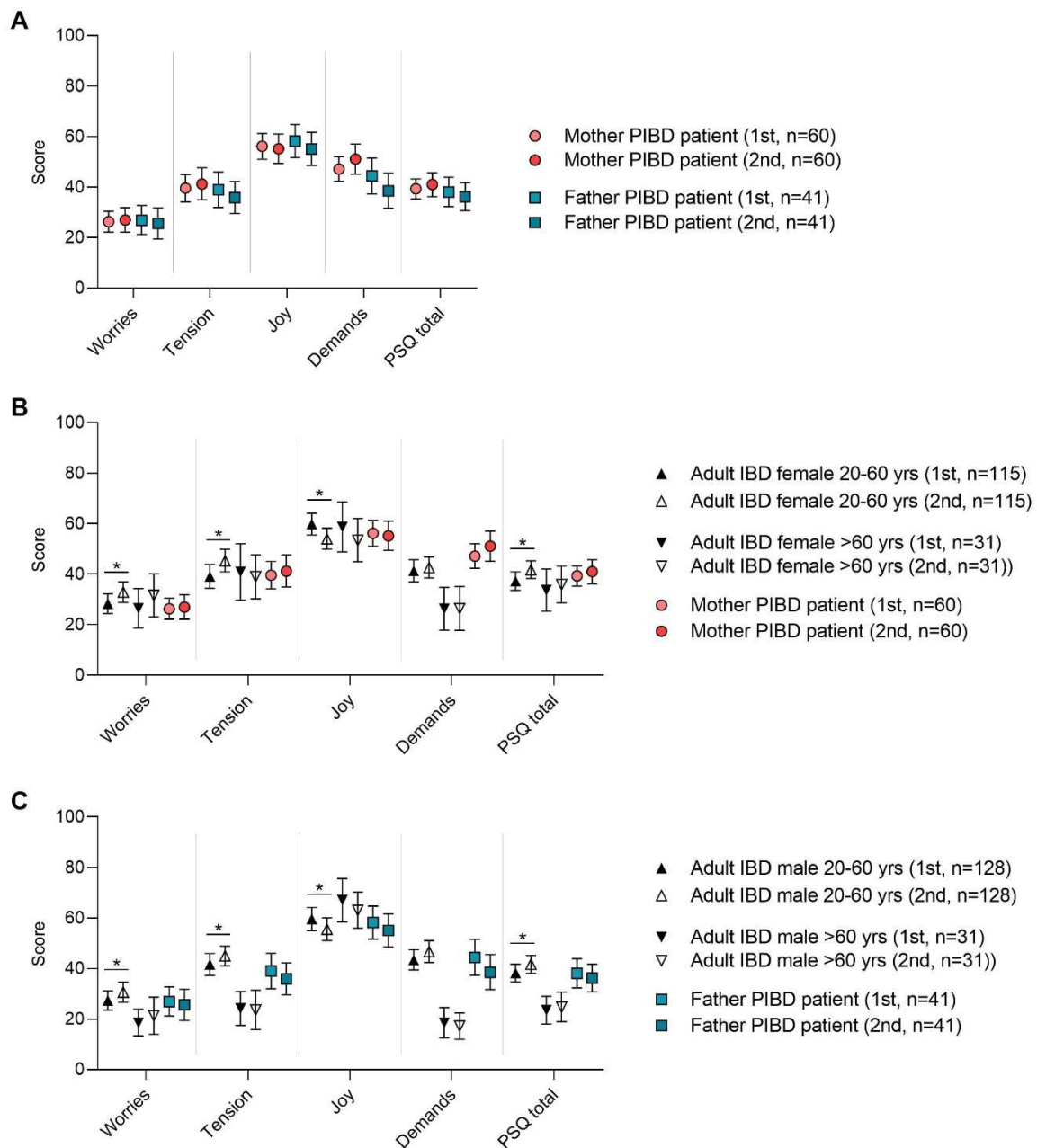


Fig. S3 Perceived Stress Questionnaire (PSQ) in first (1st) and second (2nd) survey during the COVID-19 pandemic. Psychological stress was measured in adult IBD patients and in parents of pediatric IBD (PIBD) patients using the short version of the perceived stress questionnaire (PSQ). PSQ scores range 0-100 were given in mean and 95% confidence interval. A high score reflects a high degree of perceived stress (PSQ total), worries, tension, joy, or demands. Calculating total PSQ score, joy was transformed into “lack of joy”. Results are shown for mothers and fathers of PIBD patients (**A**) and for female (**B**) and male (**C**) IBD patients according to age groups from first (light colors and filled symbols) and second (dark colors and open symbols) survey. Mothers and fathers of PIBD patients are shown in relation to adult IBD patients (**B, C**).

Supplementary Figure S4

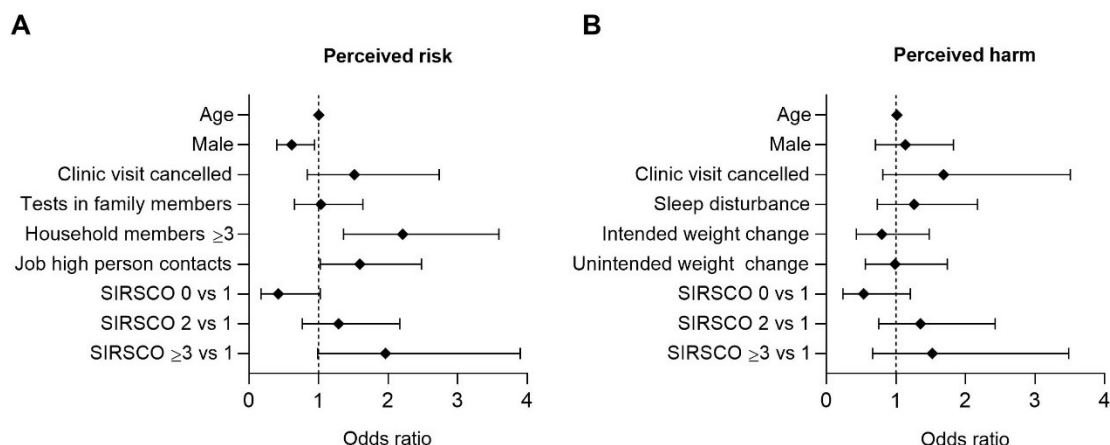


Fig. S4: Multivariable logistic regression of patients' **(A)** perceived risk to acquire COVID-19 ($n = 387$) and **(B)** perceived harm in case of infection ($n = 386$) in the second survey. SIRSCO (Scoring for increased risk for severe COVID-19 outcome) was described in Methods 2.3 and Figure S2. Mild risk with SIRSCO of 1 was performed as reference category. Other variables of the multivariable logistic regression were specified in Table S5. Odds ratios (OR) with 95% confidence intervals (95% CI) obtained from the multivariable logistic regression model are given.

Supplementary Figure S5

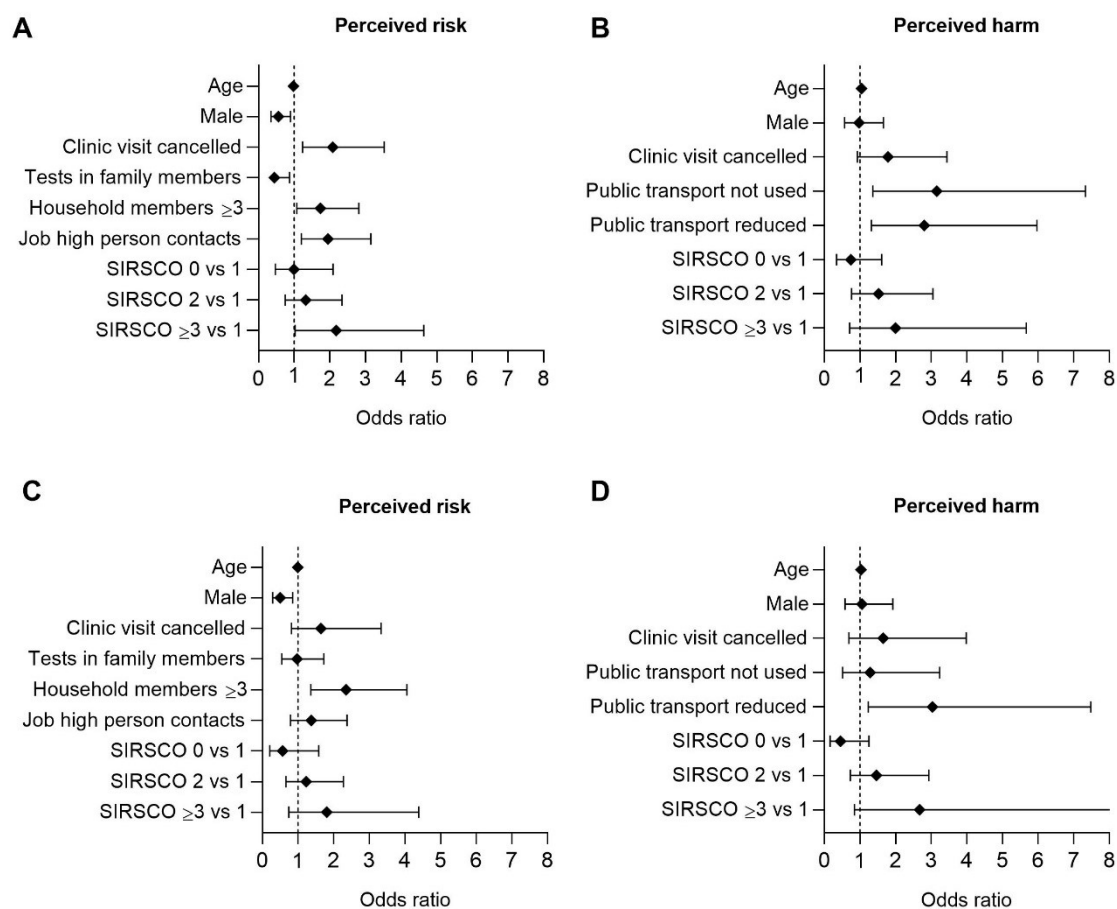


Fig. S5: Multivariable logistic regression of patients' (aged 20-60 years) perceived risk to acquire COVID-19 and perceived harm in case of infection in the first (**A and B**) and the second (**C and D**) survey. (**A**) Perceived risk, first survey (n=340). (**B**) Perceived harm, first survey (n=343). (**C**) Perceived risk, second survey (n=255). (**D**) Perceived harm, second survey (n=255). Patients between 20 to 60 years of age were included into the analysis. SIRSCO (Scoring for increased risk for severe COVID-19 outcome) was described in Methods 2.3 and Figure S2. Mild risk with SIRSCO of 1 was performed as reference category. Other variables of the multivariable logistic regression were specified in Table S5. Odds ratios (OR) with 95% confidence intervals (95% CI) obtained from the multivariable logistic regression model are given.

Supplementary Table S1: Patient characteristics of the total cohort (N=504) in four age groups (continued)

Factors, n (%)	All patients N=504 (100%)	6 – 20 y 90 (18%)	>20 – 40 y 167 (33%)	>40 – 60 y 175 (35%)	>60 y 72 (14%)	p-value ^f
Country of birth, Germany	451 (89.5)	82 (91.1)	145 (86.8)	157 (89.7)	67 (93.1)	0.48
Place of living, Munich	175 (34.7)	23 (25.6)	69 (41.3)	59 (33.7)	24 (33.3)	0.083
Smoking >1 year/lifetime	221 (45.9)	10 (14.7)	62 (37.1)	104 (59.8)	45 (62.5)	<0.001
First degree relative with IBD	67 (13.3)	14 (15.6)	22 (13.2)	22 (12.6)	9 (12.5)	0.98
Crohn's disease phenotype^a, N=290						0.34
L1 ileo-cecal	63 (21.7)	5 (11.6)	23 (23.7)	25 (22.9)	10 (24.4)	
L2 colonic	42 (14.5)	3 (7.0)	16 (16.5)	20 (18.3)	3 (7.3)	
L3 Ileo-colonic	160 (55.2)	30 (69.8)	50 (51.5)	55 (50.5)	25 (61.0)	
L4 only (upper GI incl. jejunum)	25 (8.6)	5 (11.6)	8 (8.3)	9 (8.3)	3 (7.3)	
B2 stricturing disease^b, N=295	66 (22.4)	6 (13.6)	20 (20.0)	28 (25.7)	12 (28.6)	0.46
Perianal involvement^c, N=295	135 (45.8)	16 (36.4)	49 (49.0)	55 (50.5)	15 (35.7)	0.13
Ulcerative colitis phenotype^d, N=142						0.16
E1 Proctitis	20 (14.1)	3 (12.0)	3 (6.5)	8 (17.0)	6 (25.0)	
E2 Left sided	23 (16.2)	1 (4.0)	8 (17.4)	9 (19.2)	5 (20.8)	
E3 Extensive	99 (69.7)	21 (84.0)	35 (76.1)	30 (63.8)	13 (54.2)	
Co-morbidities with increased risk for severe COVID-19 outcome						
Diabetes (Type I or Type II), N=504	27 (5.4)	2 (2.2)	0 (0.0)	15 (8.6)	10 (13.9)	<0.001
Chronic lung disease, N=504	47 (9.3)	8 (8.9)	12 (7.2)	15 (8.6)	12 (16.7)	0.13
Chronic liver disease, N=504	45 (8.9)	6 (6.7)	13 (7.8)	21 (12.0)	5 (6.9)	0.36
Chronic heart disease, N=418	19 (4.6)	0 (0.0)	1 (0.6)	4 (2.3)	14 (19.4)	<0.001
Arterial hypertension, N=418	71 (17.0)	0 (0.0)	6 (3.6)	37 (21.1)	28 (38.9)	<0.001
Renal insufficiency, N=418	19 (4.5)	0 (0.0)	5 (3.0)	9 (5.1)	5 (6.9)	0.53
Rheumatic disease, N=418	47 (11.2)	0 (0.0)	7 (4.2)	21 (12.0)	19 (26.4)	<0.001
Stroke, N=418	5 (1.2)	0 (0.0)	1 (0.6)	1 (0.6)	3 (4.2)	0.089
Malignancy, N=418	15 (3.6)	0 (0.0)	4 (2.4)	3 (1.7)	8 (11.1)	0.002
Obesity BMI ≥ 30 kg/m ² , N=504	58 (11.5)	1 (1.1)	14 (8.4)	33 (18.9)	10 (13.9)	0.0001
Categories of high-risk comorbidity, N=504						<0.0001
None	290 (57.5)	73 (81.1)	116 (69.5)	82 (46.9)	19 (26.4)	
One high-risk comorbidity	132 (26.2)	17 (18.9)	41 (24.5)	54 (30.9)	20 (27.8)	
Two high-risk comorbidities	46 (9.1)	0 (0.0)	8 (4.8)	23 (13.1)	15 (20.8)	
≥3 high-risk comorbidities	36 (7.1)	0 (0.0)	2 (1.2)	16 (9.1)	18 (25.0)	
Transplantation (organ, hematopoietic stem cell), N=504	9 (1.8)	0 (0.0)	1 (0.6)	5 (2.9)	3 (4.2)	0.092

Results were presented in frequency (n) and column percentage (%).

^{a b c d e} Phenotypes were categorized based on self-assessment of participants on IBD disease course.

^f P-values obtained from Pearson's Chi-square test or Fisher's exact test as appropriate.

Bold p-values indicate significant differences in the proportion of respective factors in 4 age groups with a p-value <0.05.

Supplementary Table S2: Univariate analysis of factors associated with high perceived risk of acquiring COVID-19 infection, N=501

Factors, N (row %)	Total cohort, N=501	Low perceived risk (rating ≤ 3) n=320 (64%)	High perceived risk (rating > 3) n=181 (36%)	p-value ^a	Crude OR (95%CI)	p-value ^b	OR adjusted for age and gender (95%CI)	p-value ^c
Age in years, median (IQR)	40 (27-54)	41 (26-56)	38 (28-50)	<0.001	0.98 (0.98 - 0.99)	<0.0001		
Age groups				0.006				
6 – 20	90	61 (68%)	29 (32%)		1.94 (1.13 – 3.28)	0.01		
>20 – 40	167	96 (57%)	71 (43%)		3.01 (2.1 - 4.36)	<0.0001		
>40 – 60	173	106 (61%)	67 (39%)		2.57 (1.84 - 3.65)	<0.0001		
>60	71	57 (80%)	14 (20%)		1			
Gender				0.004				
Female	231	132 (58%)	99 (43%)		1			
Male	270	188 (70%)	82 (31%)		0.58 (0.42 - 0.8)	0.0009		
Living in Munich				0.45				
Yes	174	115 (66%)	59 (34%)		1		1	
No	327	205 (63%)	122 (37%)		1.16 (0.82 - 1.66)	0.41	1.16 (0.82 - 1.67)	0.40
Housing space per person				0.015				
≤30m2 - small space	140	87 (62%)	53 (38%)		1		1	
30m2 to 55m2 – medium space	239	141 (59%)	98 (41%)		1.14 (0.78 - 1.69)	0.50	1.13 (0.76 - 1.68)	0.55
>55m2 - large space	118	88 (75%)	30 (25%)		0.56 (0.37 - 0.85)	0.006	0.61 (0.40 - 0.94)	0.02
Number of household members				0.009				
1 or 2	254	176 (69%)	78 (31%)		1		1	
≥3	245	142 (58%)	103 (42%)		1.64 (1.19 - 2.26)	0.003	1.68 (1.19 - 2.40)	0.004
Employment status				0.12				
Employed	314	186 (59%)	128 (41%)		1.73 (1.23 - 2.45)	0.002	1.51 (1.03 – 2.21)	0.03
Self-employed	31	22 (71%)	9 (29%)		1.03 (0.55 - 1.86)	0.92	1.09 (0.57 – 2.02)	0.79
Not working	95	68 (72%)	27 (28%)		1		1	
Net income per household				0.75				
≤2500 €	105	62 (59%)	43 (41%)		1.28 (0.81 - 2.02)	0.28	1.28 (0.80 – 2.03)	0.31
2500 to 4000 €	109	71 (65%)	38 (35%)		0.99 (0.69 - 1.43)	0.96	1.02 (0.70 – 1.47)	0.94
4000 to 6000 €	114	69 (61%)	45 (39%)		1.21 (0.88 - 1.66)	0.25	1.30 (0.94 – 1.79)	0.12
>6000 €	77	50 (65%)	27 (35%)		1		1	
Level of education				0.19				
<12 years education	201	136 (68%)	65 (32%)		1		1	
≥12 years education	283	175 (62%)	108 (38%)		1.29 (0.92 - 1.82)	0.14	1.25 (0.88 – 1.80)	0.22
High-risk job for COVID-19 infection				0.0002				
Yes	209	114 (55%)	95 (45%)		1.99 (1.44 - 2.76)	<0.0001	1.88 (1.35 – 2.61)	0.0002
No	292	206 (71%)	86 (29%)		1		1	
Public transport usage reduced				0.07				
No	59	43 (73%)	16 (27%)		1		1	
Yes	291	174 (60%)	117 (40%)		1.81 (1.01 - 3.38)	0.05	1.71 (0.95 – 3.21)	0.08
Does not apply to me	148	101 (68%)	47 (32%)		1.25 (0.69 - 2.36)	0.47	1.21 (0.67 – 2.29)	0.55

Factors, N (row %)	Total cohort, N=501	Low perceived risk (rating ≤ 3) n=320 (64%)	High perceived risk (rating > 3) n=181 (36%)	p-value ^a	Crude OR (95%CI)	p-value ^b	OR adjusted for age and gender (95%CI)	p-value ^c
Temporary incapacity to work since 3/20				0.007				
No	304	203 (67%)	101 (33%)		1		1	
Yes, due to IBD or other reasons	111	58 (52%)	53 (48%)		1.84 (1.22 - 2.77)	0.004	1.80 (1.18 – 2.74)	0.006
BMI				0.16				
Underweight	40	25 (62%)	15 (38%)		1.19 (0.6 - 2.29)	0.60	1.00 (0.50 – 1.94)	0.99
Normal weight	275	183 (67%)	92 (33%)		1		1	
Overweight	128	83 (65%)	45 (35%)		1.08 (0.82 - 1.42)	0.59	1.31 (0.98 – 1.76)	0.07
Obesity	57	29 (51%)	28 (49%)		1.92 (1.4 - 2.63)	<0.0001	2.22 (1.59 – 3.10)	<0.0001
IBD Type				0.41				
Crohn's Disease	295	183 (62%)	112 (38%)		1.17 (0.86 - 1.6)	0.33	1.13 (0.82 – 1.56)	0.45
Ulcerative Colitis / IBD-u	198	130 (66%)	68 (34%)		1		1	
Disease activity (self-assessment)				0.23				
Remission	228	146 (64%)	82 (36%)		1		1	
Mild activity	197	120 (61%)	77 (39%)		1.14 (0.82 - 1.61)	0.44	1.16 (0.83 – 1.64)	0.39
Moderate / severe activity	75	54 (72%)	21 (28%)		0.69 (0.46 - 1.03)	0.07	0.75 (0.50 – 1.13)	0.17
Duration of IBD (to 2020)				0.66				
0 to 5 years	126	86 (68%)	40 (32%)		1		1	
6 to 10 years	93	56 (60%)	37 (40%)		1.42 (0.89 - 2.3)	0.15	1.64 (1.01 – 2.69)	0.049
11 to 20 years	147	94 (64%)	53 (36%)		1.21 (0.8 - 1.86)	0.37	1.80 (1.15 – 2.88)	0.01
over 20 years	122	77 (63%)	45 (37%)		1.26 (0.83 - 1.92)	0.28	2.59 (1.57 – 4.37)	0.0003
Influenza vaccination				0.49				
Yes	203	133 (66%)	70 (34%)		0.88 (0.63 - 1.22)	0.44	0.85 (0.60 – 1.20)	0.36
No	293	183 (62%)	110 (38%)		1		1	
Any immunosuppressive medications used incl. IM, biologics, steroids				0.26				
Yes	399	250 (63%)	149 (37%)		1.3 (0.91 - 1.87)	0.15	1.37 (0.96 – 1.99)	0.09
No	102	70 (69%)	32 (31%)		1		1	
Infliximab (i.e., Remicade, Remsima, Flixabi, Inflectra, Zessly)				0.29				
Yes	165	100 (61%)	65 (39%)		1.23 (0.87 - 1.75)	0.24	1.25 (0.87 - 1.79)	0.22
No	336	220 (65%)	116 (35%)		1		1	
High-risk comorbidity				0.34				
No high-risk comorbidity	289	188 (65%)	101 (35%)		1		1	
One high-risk comorbidity	132	88 (67%)	44 (33%)		0.93 (0.65 - 1.32)	0.69	1.10 (0.76 - 1.59)	0.61
Two high-risk comorbidities	45	25 (56%)	20 (44%)		1.49 (0.98 - 2.26)	0.06	2.21 (1.39 - 3.53)	0.0008
≥3 high-risk comorbidities	35	19 (54%)	16 (46%)		1.57 (1.04 - 2.37)	0.03	2.84 (1.73 - 4.70)	<0.0001
SIRSCO^d index for severe COVID-19				0.59				
0= no increased risk	58	40 (69%)	18 (31%)		0.83 (0.45 – 1.48)	0.54	0.72 (0.39 – 1.29)	0.28
1= mild risk	248	161 (65%)	87 (35%)		1		1	
2= moderate risk	116	73 (63%)	43 (37%)		1.09 (0.82 – 1.45)	0.55	1.24 (0.92 – 1.68)	0.16
≥3= severe to very severe risk	79	46 (58%)	33 (42%)		1.33 (0.99 – 1.77)	0.06	2.23 (1.57 – 3.18)	<0.0001
Sleep disturbances				0.43				
Yes	112	68 (61%)	44 (39%)		1.19 (0.79 – 1.78)	0.40	1.17 (0.77 – 1.76)	0.46
No	386	250 (65%)	136 (35%)		1		1	

Factors, N (row %)	Total cohort, N=501	Low perceived risk (rating ≤ 3) n=320 (64%)	High perceived risk (rating > 3) n=181 (36%)	p-value ^a	Crude OR (95%CI)	p-value ^b	OR adjusted for age and gender (95%CI)	p-value ^c
Weight change				0.02				
Yes, intended	71	42 (59%)	29 (41%)		1.54 (0.93 – 2.51)	0.09	1.51 (0.90 – 2.50)	0.11
Yes, unintended	135	75 (56%)	60 (44%)		1.79 (1.35 – 2.36)	<.0001	1.82 (1.37 – 2.41)	<0.0001
Unchanged	294	203 (69%)	91 (31%)		1		1	
Food intake				0.02				
More	72	36 (50%)	36 (50%)		2.04 (1.25 – 3.32)	0.004	1.91 (1.17 – 3.13)	0.009
Unchanged	395	265 (67%)	130 (33%)		1		1	
Less	33	19 (58%)	14 (42%)		1.5 (0.98 – 2.29)	0.06	1.36 (0.88 – 2.09)	0.16
COVID-19 PCR for patient				0.62				
Yes	117	77 (66%)	40 (34%)		0.9 (0.59 – 1.34)	0.60	0.83 (0.54 – 1.26)	0.39
No	384	243 (63%)	141 (37%)		1		1	
COVID-19 PCR for family member				0.37				
Yes	99	67 (68%)	32 (32%)		0.81 (0.51 – 1.25)	0.34	0.74 (0.47 – 1.16)	0.20
No	398	250 (63%)	148 (37%)		1		1	
Appointment declined by hospital				0.17				
Yes, at least once	46	24 (52%)	22 (48%)		1.61 (0.88 – 2.95)	0.12	1.68 (0.91 – 3.10)	0.09
No, I could schedule all requested appointments	323	206 (64%)	117 (36%)		1		1	
I haven't asked for new appointment	130	88 (68%)	42 (32%)		0.84 (0.64 – 1.1)	0.20	0.83 (0.63 – 1.08)	0.16
Appointment postponed				0.004				
Yes	133	71 (53%)	62 (47%)		1.82 (1.25 – 2.65)	0.002	1.79 (1.22 – 2.62)	0.003
No (all reasons)	367	248 (68%)	119 (32%)		1		1	
Interest in future telemedicine				0.79				
Yes	247	157 (64%)	90 (36%)		1.05 (0.76 – 1.44)	0.76	1.05 (0.76 – 1.44)	0.78
No	252	163 (65%)	89 (35%)		1		1	
Quality of life obtained in pediatric patients with Impact III Questionnaire, mean (SD), N=66								
Impact III total score	76 (10)	77 (10)	73 (10)	0.09	0.97 (0.92 - 1.02)	0.19	0.97 (0.92 - 1.02)	0.26
Impact III well being	77 (14)	78 (14)	74 (13)	0.18	0.98 (0.94 - 1.02)	0.28	0.99 (0.95 - 1.02)	0.42
Impact III emotion	63 (18)	65 (18)	61 (16)	0.44	0.99 (0.96 - 1.02)	0.45	0.99 (0.95 - 1.02)	0.36
Impact III social	87 (11)	89 (10)	82 (11)	0.02	0.95 (0.90 - 0.99)	0.03	0.95 (0.9 – 1.00)	0.05
Impact III body image	71 (15)	69 (16)	75 (11)	0.20	1.03 (0.99 - 1.07)	0.15	1.03 (0.99 - 1.07)	0.12
Quality of life obtained in patients aged ≥18 with SIBDQ, mean (SD), N=419								
SIBDQ total score	53 (11)	55 (11)	52 (11)	0.001	0.98 (0.96 - 0.99)	0.006	0.98 (0.96 - 0.99)	0.009
Systemic Systems	5 (1)	5 (1)	5 (1)	0.0008	0.78 (0.67 - 0.90)	0.001	0.80 (0.68 - 0.92)	0.003
Social Function	6 (1)	6 (1)	6 (1)	0.6976	1.01 (0.87 - 1.18)	0.85	1.01 (0.86 - 1.18)	0.94
Bowel Systems	6 (1)	6 (1)	5 (1)	0.0054	0.84 (0.72 - 0.98)	0.02	0.82 (0.70 - 0.96)	0.01
Emotion Health	5 (1)	5 (1)	5 (1)	0.0003	0.77 (0.66 - 0.89)	0.0005	0.78 (0.67 - 0.91)	0.002
Perceived Stress assessed by the mother of pediatric patients using PSQ, mean (95%CI), N=81								
PSQ Total Score	42 (38 - 46)	41 (36 - 46)	43 (37 - 50)	0.60	1.006 (0.98 - 1.04)	0.64	1.01 (0.98 - 1.04)	0.47
PSQ Worries	30 (26 - 35)	30 (24 - 36)	31 (26 - 37)	0.47	1.003 (0.98 - 1.03)	0.78	1.00 (0.98 - 1.03)	0.72
PSQ Tension	42 (37 - 47)	41 (36 - 47)	43 (34 - 53)	0.96	1.004 (0.98 - 1.03)	0.73	1.01 (0.98 - 1.03)	0.53
PSQ Joy	54 (50 - 59)	54 (49 - 60)	54 (45 - 63)	0.96	1.00 (0.98 - 1.02)	0.98	1.00 (0.97 - 1.02)	0.77
PSQ Demands	50 (45 - 54)	49 (43 - 55)	52 (45 - 60)	0.49	1.008 (0.99 - 1.03)	0.50	1.01 (0.99 - 1.04)	0.30

Factors, N (row %)	Total cohort, N=501	Low perceived risk (rating ≤ 3) n=320 (64%)	High perceived risk (rating > 3) n=181 (36%)	p-value ^a	Crude OR (95%CI)	p-value ^b	OR adjusted for age and gender (95%CI)	p-value ^c
Perceived Stress assessed by adult patients using PSQ, mean (95%CI), N=393								
PSQ Total Score	37 (34 - 39)	33 (31 - 36)	42 (39 - 45)	<0.0001	1.02 (1.01 - 1.03)	<0.0001	1.02 (1.009 - 1.03)	0.0003
PSQ Worries	28 (26 - 30)	24 (22 - 27)	33 (29 - 37)	0.0004	1.02 (1.01 - 1.03)	0.0001	1.02 (1.007 - 1.03)	0.0007
PSQ Tension	40 (37 - 42)	36 (33 - 40)	46 (42 - 50)	0.0003	1.02 (1.01 - 1.02)	0.0003	1.01 (1.005 - 1.02)	0.001
PSQ Joy	59 (56 - 61)	61 (58 - 64)	54 (50 - 58)	0.007	0.989 (0.981 - 0.997)	0.009	0.989 (0.981 - 0.997)	0.01
PSQ Demands	38 (36 - 40)	35 (32 - 38)	43 (40 - 47)	0.0002	1.02 (1.01 - 1.02)	0.0007	1.01 (1.00 - 1.02)	0.004

Results were presented in frequency (n) and row percentage (%) for categorical variables, mean with 95% confidence intervals (95% CI), mean with standard deviation (SD) or median with interquartile range (IQR) for continuous variables as appropriate.

Crude odds ratios (OR) with 95% CI obtained from the univariate logistic regression model are given.

Adjusted OR resulted from the same logistic regression model as the univariate analysis adjusted for age and gender.

^a P-values refer to the comparison between group with low perceived risk (rating ≤ 3) versus group with high perceived risk (rating >3) obtained by Mann-Whitney-U-test for continuous variables, Pearson's Chi-square test, or Fisher's exact test for categorical variables, where applicable.

^b P-values calculated from the Wald Chi-Square Test for the significance of crude OR.

^c P-values calculated from the Wald Chi-Square Test for the significance of adjusted OR.

^d SIRSCO (Scoring for increased risk for severe COVID-19 outcome) was described in Methods 2.3 and S2.

PSQ, Perceived stress questionnaire; SIBDQ, Short Inflammatory Bowel Disease Questionnaire

Bold p-values indicate statistically significant results with a p-value ≤ 0.05.

Supplementary Table S3: Univariate analysis of factors associated with high perceived harm in case of COVID-19 infection, N=501

Factors, N (row %)	Total cohort, N=501	Low perceived harm (rating ≤ 3) n=123 (25%)	High perceived harm (rating > 3) n=378 (75%)	p-value ^a	Crude OR (95%CI)	p-value ^b	OR adjusted for age and gender (95%CI)	p-value ^c
Age in years, median (IQR)	40 (27 – 54)	34 (22-48)	42 (29 – 55)	0.0006	1.02 (1.01 – 1.03)	0.002		
Age groups				0.02				
6 – 20	90	27 (30%)	63 (70%)		0.57 (0.34 – 0.99)	0.04		
>20 – 40	167	51 (31%)	116 (69%)		0.56 (0.38 – 0.81)	0.002		
>40 – 60	173	31 (18%)	142 (82%)		1.13 (0.78 – 1.62)	0.53		
>60	71	14 (20%)	57 (80%)		1			
Gender				0.72				
Female	231	55 (24%)	176 (76%)		1			
Male	270	68 (25%)	202 (75%)		0.93 (0.64 – 1.33)	0.69		
Living in Munich				0.62				
Yes	174	45 (26%)	129 (74%)		1		1	
No	327	78 (24%)	249 (76%)		1.11 (0.75 – 1.63)	0.58	1.13 (0.76 – 1.66)	0.52
Housing space per person				0.73				
≤30m ² – small space	140	31 (22%)	109 (78%)		1		1	
30m ² to 55m ² – medium space	239	59 (25%)	180 (75%)		0.87 (0.55 – 1.35)	0.54	0.76 (0.48 – 1.19)	0.24
>55m ² – large space	118	31 (26%)	87 (74%)		0.8 (0.5 – 1.26)	0.34	0.61 (0.37 – 0.98)	0.047
Number of household members				0.40				
1 to 2	254	58 (23%)	196 (77%)		1		1	
≥3	245	64 (26%)	181 (74%)		0.84 (0.58 – 1.19)	0.33	1.15 (0.78 – 1.7)	0.47
Employment status				0.71				
Employed	314	74 (24%)	240 (76%)		0.87 (0.59 – 1.27)	0.46	1.2 (0.78 – 1.83)	0.41
Self-employed	31	8 (26%)	23 (74%)		0.77 (0.41 – 1.48)	0.41	1.03 (0.54 – 2.03)	0.94
Not working	95	20 (21%)	75 (79%)		1		1	
Net family income				0.2				
≤2500 €	105	27 (26%)	78 (74%)		1.31 (0.8 – 2.18)	0.29	1.03 (0.62 – 1.75)	0.91
2500 to 4000 €	109	22 (20%)	87 (80%)		1.79 (1.2 – 2.71)	0.005	1.53 (1.01 – 2.34)	0.046
4000 to 6000 €	114	22 (19%)	92 (81%)		1.89 (1.32 – 2.73)	0.0005	1.88 (1.31 – 2.72)	0.001
>6000 €	77	24 (31%)	53 (69%)		1		1	
Level of education				0.74				
<12 years education	201	50 (25%)	151 (75%)		1		1	
≥12 years education	283	69 (24%)	214 (76%)		1.03 (0.7 – 1.48)	0.89	1.28 (0.86 – 1.89)	0.22
Risk employment for COVID-19 infection				0.78				
Yes	209	50 (24%)	159 (76%)		1.06 (0.74 – 1.54)	0.76	1.17 (0.81 – 1.71)	0.42
No	292	73 (25%)	219 (75%)		1		1	
Public transport usage reduced				0.03				
No	59	22 (37%)	37 (63%)		1		1	
Yes	291	62 (21%)	229 (79%)		2.2 (1.23 – 3.83)	0.006	2.53 (1.4 – 4.48)	0.002
Does not concern me	148	38 (26%)	110 (74%)		1.72 (0.96 – 3.02)	0.06	1.84 (1.02 – 3.28)	0.04

Factors, N (row %)	Total cohort, N=501	Low perceived harm (rating ≤ 3) n=123 (25%)	High perceived harm (rating > 3) n=378 (75%)	p-value ^a	Crude OR (95%CI)	p-value ^b	OR adjusted for age and gender (95%CI)	p-value ^c
Temporary incapacity to work since 03/20				0.80				
No	304	72 (24%)	232 (76%)		1		1	
Yes, due to IBD or other reasons	111	25 (23%)	86 (77%)		1.07 (0.67 – 1.76)	0.79	1.12 (0.7 – 1.86)	0.65
BMI				0.27				
Underweight	40	11 (28%)	29 (73%)		0.97 (0.49 – 2.08)	0.94	1.24 (0.61 – 2.68)	0.57
Normal weight	275	74 (27%)	201 (73%)		1		1	
Overweight	128	28 (22%)	100 (78%)		1.32 (0.97 – 1.79)	0.08	1.15 (0.83 – 1.59)	0.40
Obesity	57	9 (16%)	48 (84%)		1.96 (1.33 – 2.97)	0.001	1.58 (1.05 – 2.43)	0.03
IBD Type				0.32				
Crohn's Disease	295	66 (22%)	229 (78%)		1.24 (0.87 – 1.77)	0.24	1.17 (0.82 – 1.68)	0.39
Ulcerative Colitis / IBD-u	198	52 (26%)	146 (74%)		1		1	
Disease activity (self-assessment)				0.11				
Remission	228	65 (29%)	163 (71%)		1		1	
Mild activity	197	39 (20%)	158 (80%)		1.62 (1.1 – 2.36)	0.01	1.57 (1.07 – 2.3)	0.02
Moderate / severe activity	75	18 (24%)	57 (76%)		1.26 (0.83 – 1.93)	0.28	1.14 (0.75 – 1.76)	0.54
Duration of IBD (to 2020)				0.30				
0 to 5 years	126	35 (28%)	91 (72%)		1		1	
6 to 10 years	93	23 (25%)	70 (75%)		1.17 (0.7 – 1.95)	0.55	1.07 (0.63 – 1.79)	0.81
11 to 20 years	147	38 (26%)	109 (74%)		1.1 (0.7 – 1.71)	0.66	0.75 (0.46 – 1.2)	0.23
over 20 years	122	22 (18%)	100 (82%)		1.75 (1.1 – 2.73)	0.02	0.84 (0.48 – 1.46)	0.54
Influenza vaccination				0.16				
Yes	203	41 (20%)	162 (80%)		1.51 (1.03 – 2.25)	0.04	1.39 (0.95 – 2.08)	0.10
No	293	81 (28%)	212 (72%)		1		1	
Any immunosuppressive medications used incl. IMM, biologics, steroids				<.001				
Yes	399	84 (21%)	315 (79%)		2.32 (1.6 – 3.37)	<0.0001	2.44 (1.67 – 3.58)	<0.0001
No	102	39 (38%)	63 (62%)		1		1	
Infliximab (i.e., Remicade, Remsima, Flixabi, Inflectra, Zessly)				0.91				
Yes	165	41 (25%)	124 (75%)		0.98 (0.66 – 1.46)	0.91	1.1 (0.74 – 1.65)	0.66
No	336	82 (24%)	254 (76%)		1		1	
High-risk comorbidity				0.08				
No high-risk comorbidity	289	82 (28%)	207 (72%)		1		1	
One high risk comorbidity	132	28 (21%)	104 (79%)		1.47 (1 – 2.18)	0.05	1.31 (0.88 – 1.97)	0.19
Two high risk comorbidities	45	9 (20%)	36 (80%)		1.59 (0.98 – 2.63)	0.07	1.29 (0.76 – 2.22)	0.35
≥3 high risk comorbidities	35	4 (11%)	31 (89%)		3.07 (1.76 – 5.66)	0.0002	2.27 (1.21 – 4.44)	0.01
SIRSCO^d index for severe COVID-19 course				0.0006				
0= no increased risk	58	21 (36%)	37 (64%)		0.74 (0.42 – 1.32)	0.29	0.72 (0.41 – 1.30)	0.26
1= mild	248	73 (29%)	175 (71%)		1			
2= moderate	116	17 (15%)	99 (85%)		2.43 (1.72 – 3.49)	<0.0001	2.28 (1.59 – 3.3)	<0.0001
≥3 severe to very severe risk	79	12 (15%)	67 (85%)		2.33 (1.63 – 3.37)	<0.0001	2.02 (1.33 – 3.09)	0.001
Sleep disturbances				0.01				
Yes	112	16 (14%)	96 (86%)		2.24 (1.33 – 4.03)	0.004	2.16 (1.27 – 3.89)	0.01
No	386	105 (27%)	281 (73%)		1		1	

Factors, N (row %)	Total cohort, N=501	Low perceived harm (rating ≤ 3) n=123 (25%)	High perceived harm (rating > 3) n=378 (75%)	p-value ^a	Crude OR (95%CI)	p-value ^b	OR adjusted for age and gender (95%CI)	p-value ^c
Weight change								
				0.007				
Yes, intended	71	15 (21%)	56 (79%)		1.54 (0.88 – 2.87)	0.15	1.92 (1.08 – 3.62)	0.03
Yes, unintended	135	21 (16%)	114 (84%)		2.24 (1.58 – 3.25)	<.0001	2.15 (1.51 – 3.13)	<0.0001
Unchanged	294	86 (29%)	208 (71%)		1		1	
Food intake since pandemic								
				0.15				
More	72	11 (15%)	61 (85%)		1.93 (1.04 – 3.94)	0.05	2.01 (1.07 – 4.13)	0.04
Unchanged	395	102 (26%)	293 (74%)		1		1	
Less	33	9 (27%)	24 (73%)		0.93 (0.59 – 1.51)	0.76	0.96 (0.6 – 1.57)	0.87
COVID-19 PCR for patient since 03/20								
				0.86				
Yes	117	28 (24%)	89 (76%)		1.04 (0.67 – 1.67)	0.85	1.17 (0.75 – 1.89)	0.51
No	384	95 (25%)	289 (75%)		1		1	
COVID-19 PCR for family member since 03/20								
				0.06				
Yes	99	23 (23%)	76 (77%)		1.07 (0.66 – 1.78)	0.80	1.19 (0.73 – 2)	0.51
No	398	97 (24%)	301 (76%)		1		1	
Appointment declined by hospital								
				0.11				
Yes, at least once	46	8 (17%)	38 (83%)		1.41 (0.68 – 3.32)	0.39	1.31 (0.62 – 3.09)	0.51
No, I could schedule all requested appointments	323	74 (23%)	249 (77%)		1		1	
I haven't asked for new appointment	130	40 (31%)	90 (69%)		0.67 (0.5 – 0.89)	0.005	0.67 (0.5 – 0.89)	0.006
Appointment postponed								
				0.001				
Yes	133	19 (14%)	114 (86%)		2.37 (1.46 – 4.07)	0.0009	2.29 (1.4 – 3.94)	0.002
No (all reasons)	367	104 (28%)	263 (72%)		1		1	
Interest in future telemedicine								
				0.55				
Yes	247	58 (23%)	189 (77%)		1.13 (0.8 – 1.62)	0.49	1.18 (0.83 – 1.71)	0.36
No	252	65 (26%)	187 (74%)		1		1	
Quality of life obtained in pediatric patients with Impact III Questionnaire, mean (SD), N=66								
Impact III total score	77 (14)	76 (15)	77 (14)	0.97	1.004 (0.95 – 1.06)	0.88	1.01 (0.96 – 1.07)	0.64
Impact III well being	63 (18)	63 (21)	64 (16)	0.91	1.004 (0.97 – 1.04)	0.81	1.02 (0.97 – 1.06)	0.45
Impact III emotion	87 (11)	88 (12)	86 (11)	0.98	1.003 (0.97 – 1.03)	0.85	0.998 (0.97 – 1.03)	0.92
Impact III social	71 (15)	68 (16)	72 (14)	0.37	0.98 (0.93 – 1.03)	0.45	0.99 (0.94 – 1.04)	0.63
Impact III body image	76 (10)	76 (11)	76 (10)	0.22	1.02 (0.99 – 1.06)	0.23	1.03 (0.99 – 1.07)	0.14
Quality of life obtained in patients aged ≥18 with SIBDQ, mean (SD), N=419								
SIBDQ total score	53 (11)	56 (11)	53 (11)	0.0008	0.97 (0.95 – 0.99)	0.005	0.97 (0.95 – 0.99)	0.01
Systemic Systems	5 (1)	6 (1)	5 (1)	0.0006	0.74 (0.61 – 0.88)	0.001	0.74 (0.61 – 0.89)	0.001
Social Function	6 (1)	6 (1)	6 (1)	0.04	0.87 (0.71 – 1.04)	0.15	0.89 (0.73 – 1.07)	0.24
Bowel Systems	6 (1)	6 (1)	6 (1)	0.05	0.86 (0.71 – 1.03)	0.10	0.88 (0.73 – 1.06)	0.18
Emotion Health	5 (1)	5 (1)	5 (1)	0.001	0.74 (0.61 – 0.89)	0.001	0.73 (0.6 – 0.88)	0.001
Perceived Stress assessed by the mother of pediatric patients using PSQ, mean (95%CI), N=81								
PSQ Total Score	42 (38 – 46)	40 (33 – 47)	43 (38 – 47)	0.74	1.01 (0.98 – 1.04)	0.58	1.01 (0.98 – 1.04)	0.44
PSQ Worries	30 (26 – 35)	28 (20 – 36)	31 (26 – 37)	0.55	1.01 (0.98 – 1.04)	0.50	1.01 (0.98 – 1.04)	0.60
PSQ Tension	42 (37 – 47)	39 (30 – 47)	43 (37 – 49)	0.49	1.01 (0.99 – 1.03)	0.40	1.01 (0.99 – 1.04)	0.38

Factors, N (row %)	Total cohort, N=501	Low perceived harm (rating ≤ 3) n=123 (25%)	High perceived harm (rating > 3) n=378 (75%)	p-value ^a	Crude OR (95%CI)	p-value ^b	OR adjusted for age and gender (95%CI)	p-value ^c
PSQ Joy	54 (50 – 59)	56 (48 – 63)	54 (48 – 60)	0.76	0.995 (0.973 – 1.017)	0.66	0.99 (0.97 – 1.01)	0.44
PSQ Demands	50 (45 – 54)	49 (38 – 59)	51 (46 – 56)	0.77	1.01 (0.98 – 1.03)	0.70	1.01 (0.99 – 1.04)	0.40
Perceived Stress assessed by adult patients using PSQ, mean (95%CI), N=393								
PSQ Total Score	37 (34 – 39)	30 (26 – 34)	39 (36 – 41)	0.0007	1.02 (1.01 – 1.04)	0.0004	1.03 (1.01 – 1.04)	0.0001
PSQ Worries	28 (26 – 30)	20 (17 – 24)	30 (28 – 33)	<.0001	1.03 (1.01 – 1.04)	<.0001	1.03 (1.02 – 1.04)	<0.0001
PSQ Tension	40 (37 – 42)	35 (30 – 39)	42 (39 – 45)	0.03	1.011 (1.002 – 1.02)	0.02	1.013 (1.003 – 1.023)	0.01
PSQ Joy	59 (56 – 61)	67 (62 – 72)	56 (53 – 59)	0.0002	0.98 (0.97 – 0.99)	0.0003	0.98 (0.97 – 0.99)	0.0003
PSQ Demands	38 (36 – 40)	33 (29 – 38)	40 (37 – 42)	0.02	1.012 (1.002 – 1.02)	0.02	1.015 (1.004 – 1.026)	0.007

Results were presented in frequency (n) and row percentage (%) for categorical variables, mean with 95% confidence intervals (95% CI), mean with standard deviation (SD) or median with interquartile range (IQR) for continuous variables as appropriate.

Crude odds ratios (OR) with 95% CI obtained from the univariate logistic regression model are given.

Adjusted OR resulted from the same logistic regression model as the univariate analysis adjusted for age (years) and gender.

^a P-values refer to the comparison between group with low perceived harm (rating ≤ 3) versus group with high perceived harm (rating >3) obtained by Mann-Whitney-U-test for continuous variables, Pearson's Chi-square test, or Fisher's exact test for categorical variables, where applicable.

^b P-values calculated from the Wald Chi-Square Test for the significance of crude OR.

^c P-values calculated from the Wald Chi-Square Test for the significance of adjusted OR.

^d SIRSCO (Scoring for increased risk for severe COVID-19 outcome) was described in Methods 2.3 and S2.

PSQ, Perceived stress questionnaire; SIBDQ, Short Inflammatory Bowel Disease Questionnaire

Bold p-values indicate statistically significant results with a p-value ≤ 0.05.

Supplementary Table S4: Considered variables for multivariable logistic regression

A univariate logistic analysis was performed including all subjects to determine the associations between variables of interest and high perceived risk or high perceived harm. All statistically significant variables associated with high perceived risk or high perceived harm ($p \leq 0.25$) in the univariate analysis were considered in the multivariable logistic regression. Reference category (ref.) was chosen according to clinician interest or as the most frequent category present in the considered variables.

Domains	Variable of interest
Demographics	Age in years
	Gender, categorized in Male vs. Female (ref.)
	Living in Munich, categorized in Yes (ref.) vs. No
Socio-economics	Housing space per person, categorized in <ul style="list-style-type: none"> small space ($\leq 30\text{m}^2$ per person) (ref.) middle space (30m^2 to 55m^2) large space ($>55\text{m}^2$)
	Number of family members per household, categorized in <ul style="list-style-type: none"> 1-2 persons per household (ref.) ≥ 3 persons per household
	Current employment status, categorized in <ul style="list-style-type: none"> Employed Self-employed Not working includes unemployed, retired, parental leave, sabbatical, students (ref.)
	Level of education according to the German school system, categorized in <ul style="list-style-type: none"> <12 years education (ref.) ≥ 12 years education
COVID-19 related factors	High-risk job for COVID-19 infection was considered, if patients answered as employees in the healthcare sector (e.g., nursing home, hospital, general praxis), emergency service (e.g., fire department, police), airport and air traffic (pilots, flight attendants), public transport (e.g., bus driver, train attendant, subway driver), education (e.g., kindergarten, day care, school), sales (e.g., grocery store, hardware store, drugstore), social work and other employment involved contacts with people outside of their own families. Answers: Yes vs. No (ref.)
	Public transport usage reduced <ul style="list-style-type: none"> No (ref.) Yes No need
	COVID-19 PCR for patient since 03/20: Yes vs. No (ref.)
	COVID-19 PCR for family member since 03/20: Yes vs. No (ref.)
Health conditions	BMI (kg/m^2) was calculated for all adult patients ≥ 20 years, categorized in 4 nutrition status according to WHO. <ul style="list-style-type: none"> Underweight for BMI $< 18.5 \text{ kg}/\text{m}^2$ Normal weight for BMI in $18.5\text{--}24.9 \text{ kg}/\text{m}^2$ (ref.) Overweight for BMI in $25.0\text{--}29.9 \text{ kg}/\text{m}^2$ Obesity for BMI $\geq 30 \text{ kg}/\text{m}^2$ BMI Z-scores for all children aged ≥ 6 to <20 was calculated based on WHO/CDC Growth chart 2000. Interpretation of cut-offs as follows <ul style="list-style-type: none"> Underweight/Wasting $<-1\text{SD}$ Normal weight: $\geq -1\text{SD}$ and $<+1\text{SD}$ Overweight: $\geq +1\text{SD}$ Obesity: $\geq +2\text{SD}$
	IBD Type: Crohn's Disease and Ulcerative Colitis / IBD-u (ref.)
	Disease activity (self-assessment) <ul style="list-style-type: none"> Remission (ref.) Mild activity Moderate / severe activity
	Duration of IBD (to 2020) <ul style="list-style-type: none"> 0 to 5 years (ref.) 6 to 10 years 11 to 20 years over 20 years

Domains	Variable of interest
	Influenza vaccination: Yes vs. No (ref.)
	Any immunosuppressive medications used incl. IM, biologics, steroids: Yes vs. No (ref.)
	Infliximab (i.e., Remicade, Remsima, Flixabi, Inflectra, Zessly): Yes vs. No (ref.)
	High-risk comorbidity (S2) <ul style="list-style-type: none"> No high-risk comorbidity (ref.) One high risk comorbidity Two high risk comorbidities ≥3 high risk comorbidities
	SIRSCO index for severe COVID-19 (S2) <ul style="list-style-type: none"> 0= no increased risk 1= mild risk (ref.) 2= moderate risk ≥3= severe to very severe risk
Lifestyle factors	Sleep disturbances since pandemic: Yes vs. No (ref.)
	Weight change, independent if weight gain or weight loss. <ul style="list-style-type: none"> Yes, intended Yes, unintended Unchanged (ref.)
Clinical care	Appointment declined by hospital <ul style="list-style-type: none"> Yes, at least once No, I could schedule all requested appointments (ref.) I haven't asked for new appointment
	Appointment postponed: Yes vs. No with all reasons (ref.)
	Interest in future telemedicine: Yes vs. No (ref.)

Employment status correlates significantly with net income per household ($p < 0.0001$) and temporary incapacity to work since 3/20 ($p = 0.004$). Due to missing data and to avoid multicollinearity, net income per household and temporary incapacity to work since 3/20 were excluded in the stepwise selection for multivariable logistic regression.

Food intake and weight change were highly significant correlated ($p < 0.0001$). Food intake was excluded in the stepwise selection for multivariable logistic regression due to its possibly greater recall bias than weight change.