Impact of COVID-19 on quality of life of the survivor, partner and family members

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Impact of COVID-19 on quality of life of the survivor, partner and family members

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ABSTRACT

Objective:

This study aimed to measure the impact of COVID-19 on the quality of life (QoL) of survivors and their partners and family members.

Design and Setting:

A prospective cross-sectional global online survey using social media.

Participants:

COVID-19 patients and partners or family members (age ≥18 years).

Intervention:

Online survey from June to August 2020.

Main outcome measure:

The EQ-5D-3L to measure the QoL of survivors of COVID-19, and the Family Reported Outcome Measure (FROM-16) to assess the impact on their partner/family member's QoL.

Results:

The survey was completed by 735 COVID-19 survivors (mean age=48 years; females=563) at a mean of 12.8 weeks after diagnosis and by 571 partners and 164 family members (n=735; mean age=47 years; females=246) from Europe (50.6%), North America (38.5%) and rest of the world (10.9%). The EQ-5D mean score for COVID-19 survivors was 8.65 (SD=1.9, median=9; range=6-14). 81.1% (596/735) reported pain and discomfort, 79.5% (584/735) problems with usual activities, 68.7% (505/735) anxiety and depression and 56.2% (413/735) problems with mobility. Hospitalised survivors(20 %, n=148) and survivors with pre-existing health conditions (30%, n=227) reported significantly more problems with mobility and usual activities ($p<0.05$), with hospitalised also experiencing more impact on self-care ($p\leq0.001$).

Among 735 partners and family members, the mean FROM-16 score (maximum score = highest impact =32) was 15 (median=15, range=0-32). 93.6% (688/735) reported being worried, 81.7% (601/735) frustrated, 78.4% (676/735) sad, 83.3 % (612/735) reported impact on their family activities, 68.9% (507/735) on sleep and 68.1% (500/735) on their sex life.

Conclusion:

COVID-19 survivors reported a major persisting impact on their physical and psychosocial health. The lives of their partners and other family members were also severely affected. There is a need for a holistic support system sensitive to the needs of COVID-19 survivors and their family members who experience a major "secondary burden".

Keywords

COVID-19; Long COVID, family impact; partner impact; patient impact; EQ-5D; quality of life; FROM-16; Family- Reported Outcome Measure.

Strengths and Limitations of this study

- This study provides evidence of the impact on quality of life (QoL) of 'Long COVID' in survivors of COVID-19.
- This study fills an important knowledge gap in measuring the impact of survivors' COVID-19 on the QoL of partners and other family members.
- Large sample size and heterogenous population
- Use of validated tools to assess QoL impact.
- The study was open to COVID survivors and their family members internationally, but only those active on social media who could read and understand English completed the survey.
- Causal relationships cannot be established among the study variables as the study was cross-sectional.

INTRODUCTION

The COVID-19 pandemic is causing profound changes across the world, but there is little information on its physical and psychosocial impact on survivors and their families. Despite the need (1) for information on the lived experience of infected individuals and their family members, there are only sparse data available.

It is important to ascertain COVID-19's immediate and persisting (Long COVID) impact on those affected and on their families in order to aid healthcare workers and government agencies to better support them. The understanding of how a person's health condition impacts the quality of life (QoL) of other family members has increased over the last decade (2). Various questionnaires have been developed to measure this impact, but these are mostly disease specific. A generic measure, the Family Reported Outcome Measure (FROM-16) has been validated across all areas of medicine (3-5) and is therefore suitable for measuring the impact of COVID-19 on the partner and family members of those affected. As it is a generic measure, data generated can be compared with data from other medical conditions.

The aim of this study was to assess the impact of COVID-19 on survivors and their family members based on their lived experience of COVID-19 using validated QoL instruments administered using online social media platforms.

METHODS

Settings and participants

This was a prospective cross-sectional global online survey, using an anonymous online questionnaire. The survey was carried out using https://www.onlinesurveys.ac.uk/ on a Jisc platform (6). The survey was distributed through social media platforms including Facebook, Twitter, LinkedIn, WhatsApp and Reddit.

Procedure

Ethics approval was granted by the Cardiff University School of Medicine Research Ethics Committee (SMREC 20/60). Study participants were provided with information about the study via a link in the survey to a "Participant Information Sheet" where they were informed that participation was voluntary, and their data would remain anonymous. Those who decided to take part gave informed consent at the beginning of the survey. Data collection took place from 30th May to 30th August 2020.

The study was only open to individuals who were diagnosed with COVID-19 and their family member or partner, adults aged 18 years or above who could read and understand English, and who were able to give written consent and complete the questionnaire using an electronic device. Participants were excluded if they had not had COVID-19 or if they were less than 18 years of age.

Survey development

The survey included two QoL questionnaires: EQ-5D 3-Level and FROM-16. There were additional socio-demographic questions such as responder's age, gender and country of residence (Table 1). A pre-test draft survey was piloted during May 2020 in 20 individuals without COVID-19 across several countries including the UK, India, and the UAE. Views were also sought from the study research partners, a patient and two family members. The survey questions were revised based on the collective feedback.

Patient and public involvement

Two patients and one family member were involved as integral study research partners, one of whom (SJN) is a co-author. They were involved in reviewing the study protocol, drafting the survey, reviewing the manuscript and providing suggestions from the patient and family perspective.

Survey structure

The survey had two sections. Section one was completed by the COVID-19 survivor. Each survivor provided basic demographic details and provided EQ-5D responses. Section two was completed by the partner or a close family member of the survivor who provided basic demographic details and completed FROM-16.

Measurement tools

The EQ-5D is a self-reported generic health-related QoL (HRQoL) instrument that specifically addresses health status (7). It consists of five questions on mobility, self-care, usual activities, pain and discomfort, and anxiety and depression with 3-point response categories (1= no problems, 2= some problems and 3= serious or extreme problems). The EQ-VAS component of EQ-5D asks respondents to rate their overall health status from 0 (worst imaginable health) to 100 (best imaginable health).

The FROM-16 measures the impact of a patient's disease on the QoL of a family member or partner of a patient (3). The FROM-16 comprises 16 items with 3-point response options for each: not at all (scoring 0), a little (1) and a lot (2), with a total score range of 0 - 32. The higher the score, the greater the negative impact on the family member's QoL. The 16 items are divided into two domains: Emotional (six items, maximum score12) and Personal and Social Life (ten items, maximum score 20). The FROM-16 has proven psychometric properties, a rapid completion time of two minutes (3) and translations are available in several languages (4).

Outcome*:* The primary outcome was to measure the impact of COVID-19 on survivors and their partners and family members.

Exposure: Person's COVID-19 infection and its impact on partners and family members.

Covariates: The covariates included hospital stay due to COVID-19 infection, existing health condition of survivors, duration of COVID-19 infection, partners and family members who also developed COVID-19, family members' relationship to survivors, country of residence, age and sex of family members and survivors.

Missing data: There were no missing data, but two responses were ambiguous for one of the variables (EQ-5D-VAS) and were excluded from the analysis.

Statistical analysis

Descriptive analyses were performed for all variables. The Shapiro–Wilk test was used to examine normal distribution of continuous variables. The required assumptions for normal distribution were not met. Consequently, data analysis employed non-parametric statistical method. To determine differences between groups defined by each outcome, chi-square tests (when appropriate, Fisher's exact tests) and Mann-Whitney U tests were computed. Spearman's rank correlation coefficient and multiple regression analysis were conducted to understand the effect of independent variables (i.e. predictors) on the EQ-5D and FROM-16 outcomes. Statistical Product and Service Solutions SPSS® (version 25) was used and the probability of type I error was set at $p < 0.05$.

RESULTS

Sociodemographic characteristics of the study participants

A total of 1,254 respondents consented to participate in the survey: 765 completed both sections. Thirty responses were excluded as the respondents were below the age of 18 years. The final analysis included 735 COVID-19 survivors and their family members/partner from Europe (50.6%), North America (38.5%) and the rest of the world (10.9%) (Table 1).

Table 1 Sociodemographic characteristics of the study participants

Variables	Categories	N (%) or N(SD)
COVID-19 Survivors (n=735)		
Gender	Male	172 (23.4%)
	Female	563 (76.6%)
Age (years)	Mean (SD)	47.77 (11.656)

	Median	48.00
	Range	19-85
Duration of COVID-19 (weeks)	Mean (SD)	12.76 (6.104)
	Median	13.00
	Range	1-36
	≥4 weeks	98 (13.3%)
	5-11 weeks	170 (23.1%)
	≥12 weeks	467 (63.5%)
Occupation	Unemployed	19 (2.6%)
	In paid work	538 (73.2%)
	In education or training	26 (3.5%)
	In unpaid work	7 (1%)
	Work in the home/manage the family	60 (8.2%)
	Retired	66 (9%)
	Rather not say	19 (2.6%)
Pre-existing health conditions	Yes	508 (69.1%)
	No	227 (30.9%)
Hospitalised for COVID-19	No	587 (79.9%)
	Yes	148 (20.1%)
Regions	Europe	372 (50.6%)
	North America	283 (38.5%)
	Rest of the World	80 (10.9%)
Family members (N=735)		
Gender	Male	489 (66.5%)
	Female	246 (33.5%)
Age (years)	Mean (SD)	47.43 (13.582)
	Median	48.00
	Range	18-87
Occupation	Unemployed	42 (5.7%)
	In paid work	530 (72.1%)
	In education or training	29 (3.9%)
	In unpaid work	18 (2.4%)
	Retired	95 (12.9%)
	Rather not say	21 (2.9%)
Relationship to the person affected with COVID-19	Spouse/Partner	571 (77.7%)
	Parents	48 (6.5%)
	Son/Daughter	77 (10.5%)
	Brother/Sister	24 (3.3%)
	Other	15 (2%)
Diagnosed with COVID-19	No	380 (51.7%)
	Yes	355 (48.3%)

Of the 735 COVID-19 survivors, 76.6% were females (mean and median age=48 years) and 73.3% were in paid employment. The mean time since COVID-19 symptoms started was 12.8 weeks (median=13 weeks). In 86.6% (n=637) > 4 weeks had elapsed since COVID-19 symptoms started and in 63.5% (n=467) >12 weeks had elapsed. Of the family members (mean age=48 years, median=47 years), 66.5 % were male and 72.1% were in paid employment. Most of the family members were partners (77.7%), followed by sons and daughters (10.5%) and parents (6.5%). In addition, 48.3 % of the family members had also contracted COVID-19 (Table 1).

Quality of life impact of COVID-19 on survivors

The EQ-5D mean score was 1.73 (SD=0.39) with the 'usual activities' item scoring the highest (mean=2.06, max 3) followed by pain/discomfort (1.93) and anxiety/depression (1.84). The mean score of the visual analogue part of EQ-5D was 55 (SD=22.94) (Table 2).

Table 2 Mean scores of EQ-5D and FROM-16 (n=735)

Scale	Mean (SD)	Median (interquartile range)	Range
EQ-5D-3L domains			
Overall	8.65 (1.97)	9 (3)	6-14
Mobility	1.59 (0.54)	2 (1)	1-3
Self-Care	1.23 (0.45)	1 (0)	1-3
Usual Activities	**2.06** (0.68)	2 (1)	1-3
Pain / Discomfort	**1.93** (0.56)	2 (0)	1-3
Anxiety / Depression	**1.84** (0.67)	2 (1)	1-3
EQ-VAS n(733)	55.83 (22.94)	60(35)	3-100
FROM-16			
Overall	15.00 (8.05)	15 (13)	0-32
Emotional Domain	6.12 (3.23)	6.0 (5)	0-12
Worried	**1.43** (0.61)	1 (1)	0-3
Angry	0.75 (0.73)	1(1)	0-3
Sad	**1.05 (**0.70)	1 (1)	0-3
Frustrated	**1.24 (**0.74)	1 (1)	0-3
Talking about thoughts	0.84 (0.79)	1 (1)	0-3

Difficulty caring	0.81 (0.76)	1 (1)	0-3
Personal and Social Domain	8.88 (5.51)	9.0 (9)	0-20
Time for self	0.74 (0.76)	1 (1)	0-3
Everyday travel	0.63 (0.78)	0 (1)	0-3
Eating habits	0.65 (0.73)	0 (1)	0-3
Family activities	**1.26** (0.73)	1 (1)	0-3
Holiday	**1.10** (0.88)	1 (2)	0-3
Sex life	**1.09** (0.85)	1 (2)	0-3
Work or study	0.84 (0.79)	1 (1)	0-3
Family Relationship	0.73 (0.76)	1 (1)	0-3
Family expenses	0.83 (0.82)	1 (2)	0-3
Sleep	**1.01** (0.79)	1(2)	0-3

Of the five dimensions of EQ-5D, ‘pain and discomfort’ was the impact most frequently reported (81.1%; 68.7 % some problems and 12.4% extreme problems), followed by usual activities (79.5%; 53.2% and 26.3%) and anxiety and depression (68.7%; 53.3% and 15.4%). There was a significant gender difference for ‘mobility’ and for ‘pain and discomfort’ ($p \leq 0.05$) with females being more impacted than males (Fig 1).

There was no significant difference in EQ-5D mean scores between survivors with an existing health condition (30.9%) and those without, except for mobility and usual activities ($p \leq 0.05$) (Table 3). There was a significant difference between the survivors who had been hospitalised for COVID-19 (20%) and those who had not, with the hospitalised survivors being more severely affected across mobility, self-care ($p \leq 0.001$) and usual activities ($p \leq 0.02$) (Table 3).

There were significant differences in EQ-5D mean scores between survivors with respect to onset of COVID-19 symptoms ($p<0.001$). Mean EQ-5D scores of survivors having COVID-19 symptoms for up to 4 weeks was 8.03 (SD=1.97), 5-11 weeks was 8.3 (SD=2.13) and 12 weeks and above was 8.9 (SD=1.86).

Quality of life impact of COVID-19 on family members

The mean FROM-16 score was 15, reflecting the extent of the impact of the survivors' COVID-19 on the HRQoL of their family members (Table 2). The mean score of each of the 16 items is given in Table 2 with 'Feeling worried' scoring highest (1.46) followed by family activities, frustration, holiday, and sex life (1.26, 1.24, 1.10 and 1.09, respectively) (Table 2).

Table 3 Comparisons* of EQ-5D scores for gender, pre-existing health condition and hospitalisation

EQ-5D domain	Gender Mean score		p-value**	Pre-existing health condition Mean score		p-value**	Hospitalised for COVID-19 Mean score		p-value**
	Male (n=172)	Female (n=563)		Yes (n=227)	No (n=508)		Yes (n=148)	No (n=587)	
Overall	8.33	8.74	**0.036**	8.89	8.54	**0.012**	9.17	8.51	**0.001**
Mobility	1.51	1.61	**0.037**	1.67	1.55	**0.006**	1.75	1.54	**0.0001**
Self-Care	1.22	1.24	0.602	1.28	1.21	0.053	1.36	1.20	**0.0001**
Usual Activities	1.97	2.08	0.065	2.14	2.02	**0.034**	2.19	2.02	**0.009**
Pain / Discomfort	1.82	1.97	**0.002**	1.93	1.94	0.989	1.99	1.92	0.141
Anxiety / Depression	1.81	1.85	0.611	1.88	1.82	0.289	1.88	1.83	0.427

*Mann Whitney U test

**p values were calculated using mean rank scores but mean scores are presented here for ease of understanding.

Of the FROM-16 items, the feeling of being worried was most frequently reported (93.6%; 44.6% a little, 49% a lot), followed by family activities (83.3%; 41% , 42.3%), feeling of frustration (81.7%; 39.7% , 42%), feeling sad (78.4%; 51.2%, 27.2 %), sleep (68.9%; 37.1%, 31.8 %) and sex life (68.1%; 26.7%, 41.4%) (Fig 2).

There was a significant gender difference among family members, with females feeling more sad, experiencing more impact on everyday travel (p≤ 0.01) and on their sleep p≤0.05). The impact on sex life was experienced significantly more by males than females (p≤ 0.001) (Table 4).

Table 4 Comparisons* of FROM-16 scores for gender and for whether diagnosed with COVID-19 (n=735)

FROM-16 Items	Gender Mean score		p-value**	Diagnosed with COVID-19 Mean score		p-value**
	Male (n=489)	Female (n=246)		Yes (n=355)	No (n=380)	
Overall	14.81	15.36	0.401	15.74	14.32	**0.017**
Worried	1.40	1.48	0.068	1.46	1.39	0.135
Angry	0.73	0.79	0.332	0.77	0.74	0.519
Sad	1.00	1.16	**0.004**	1.09	1.03	0.225
Frustrated	1.23	1.26	0.569	1.30	1.18	0.054
Talking about thoughts	0.83	0.87	0.651	0.89	0.80	0.132
Difficulty caring	0.79	0.85	0.324	0.81	0.80	0.847
Time for self	0.70	0.83	**0.036**	0.78	0.71	0.164
Everyday travel	0.58	0.72	**0.048**	0.64	0.62	0.874
Eating habits	0.64	0.67	0.565	0.72	0.59	**0.015**
Family activities	1.28	1.21	0.144	1.32	1.20	**0.041**
Holiday	1.10	1.10	0.992	1.17	1.03	**0.030**
Sex life	1.22	0.84	**0.000**	1.17	1.03	**0.035**
Work or study	0.83	0.87	0.485	0.92	0.77	**0.013**
Family relationships	0.69	0.79	0.109	0.75	0.70	0.281
Family expenses	0.81	0.87	0.367	0.84	0.83	0.759
Sleep	0.98	1.07	0.138	1.12	0.90	**0.000**

*Mann Whitney U test
**p values were calculated using mean rank scores but mean scores are presented here for ease of understanding.

Those with a COVID-19 history experienced a greater impact on eating habits, work and study, family activities, holiday, (p≤0.05), sex life and sleep (p≤0.001). There were no significant differences for the remaining 10 items of FROM-16 (Table 4 and Fig 3).

There were significant differences in FROM-16 mean scores between family members of survivors with respect to onset of COVID-19 symptoms ($p<0.01$). Mean FROM-16 scores of family members of survivors having COVID-19 symptoms for up to 4 weeks was 16.11 (SD=7.35), 5-11 weeks was 13.31 (SD=7.77) and 12 weeks and above was 15.38 (SD=8.21).

Relationship between the quality of life of survivors and their family members

There were significant positive correlations between the EQ-5D score and the survivors' gender, hospital stay, existing health condition and time since COVID-19 onset ($p<0.05$, $p < 0.001$) (Table 5).

There was a significant positive association between the family members' FROM-16 scores and the survivors' EQ-5D scores ($p<0 .001$) (Fig 4) and a significant negative association between FROM-16 scores and the family members' age, survivors' age and EQ-VAS scores ($p < 0.05$).

The EQ-VAS scores showed a significant inverse relationship with EQ-5D ($p<0.01$). However, other variables such as hospital stay, existing health condition, number of weeks since COVID-19, survivors' age and gender indicated that being female or being older was associated with lower EQ-VAS scores ($p < 0.05$), that is lower health status.

Can quality of life predict outcomes?

The results of multiple regression analyses indicated that survivors' demographics, duration of COVID-19 and hospital stay were significant predictors of the extent of impact on QoL of the survivor ($p=0.001$) while the survivors' pre-existing condition was not a predictor (Tables 6). Inclusion of variables such as EQ-5D scores, family members' COVID-19 history, family members' gender and relationship to the survivor in the model predicted family reported outcomes ($p=0.001$)

while family members' age, survivors' age, duration of COVID-19, pre-existing health condition and hospital stay were not significant predictors of QoL of family members (Table 7). The multiple regression analyses confirmed that the QoL of family members/partner was more impacted than survivors, female family members were affected more than males, family members with a history of COVID-19 were affected more than those without and partners were affected substantially more than those of other relationships. In addition, the model predicted that younger survivors' functional behaviour (both physical and psychosocial) was more impacted by COVID-19.

Table 5 Correlations* between the quality of life scores and socio-demographics (n=753)

		1	2	3	4	5	6	7	8	9	10
1	EQ-5D score	--									
2	FROM-16 score	0.467**	--								
3	EQ-VAS (n=733)	-0.591**	-0.346**	--							
4	COVID-19 survivor age (years)	-0.020	-0.118*	-0.075	--						
5	COVID-19 survivor gender	0.077*	-0.024	-0.102*	0.064	--					
6	Stayed in a hospital for COVID-19	0.127*	0.073	-0.097*	0.143*	-0.091*	--				
7	Survivor pre-existing health condition	0.093*	0.066	-0.104*	0.201**	0.036	0.134*	--			
8	Duration of COVID-19(weeks)	0.164*	0.029	-0.218	0.158*	0.032	0.097*	0.042	--		
9	Family member age (years)	-0.015	-0.077	-0.025	0.535**	0.066	0.034	0.145*	0.108*	--	
10	Family member gender	-0.030	0.031	0.032	-0.008	-0.507**	0.097*	0.050	-0.034	-0.113*	--

*$p \le 0.05$, **$p \le 0.01$, 2-tailed.

Table 6 Summary of survivors' characteristics predicting EQ-5D scores* (n=735)

	Unstandardised coefficients		Standardised coefficients		95% confidence interval levels for *B*					
Predictor	*B*	*Std. Error*	*Beta*	*p-value*	*Lower level*	*Upper Level*	*R^2*	*Adjusted R^2*	*F-test*	*p-value*
							0.058	0.051	8.907	0.0001
Survivor Age	-0.013	0.006	-0.076	0.043	-0.025	0.000				
Pre-existing health condition	0.298	0.157	0.070	0.059	-0.011	0.607				
Hospital stay for COVID-19	0.644	0.181	0.131	0.0001	0.288	1.001				
Duration of COVID-19 (weeks)	0.050	0.012	0.154	0.0001	0.027	0.073				
Survivor gender	-0.471	0.169	-0.101	0.005	-0.802	-0.139				

*Multiple regression; *B=the slope of the line between the predictor variable and the dependent variable – the larger the number, the more spread out the points are from the regression line; F-test=degree of the linear regression model fitting the data; R^2 = how well the model fits the data*

Table 7 Summary of family member/partner characteristics predicting FROM-16 scores (n=753)

	Unstandardised coefficients		Standardised coefficients		95% confidence interval levels for *B*					
Predictor	*B*	*Std. Error*	*Beta*	*p-value*	*Lower Level*	*Upper Level*	*R^2*	*Adjusted R^2*	*F-test*	*p-val*
							0.272	0.260	22.506	0.0001
EQ-5D score	2.019	0.134	0.495	0.001	1.757	2.282				
Age family member	-0.044	0.030	-0.073	0.144	-0.102	0.015				
Survivor's duration of COVID-19 (weeks)	-0.064	0.043	-0.048	0.144	-0.149	0.022				
Family member gender	-1.357	0.587	-0.080	0.021	-2.510	-0.204				
Have you also had COVID-19?	1.138	0.524	0.071	0.030	0.109	2.167				
Relationship										
parent	-1.061	1.204	-0.033	0.379	-3.426	1.303				
sons and daughters	-3.243	1.108	-0.123	0.004	-5.419	-1.067				
brothers and sisters	-4.079	1.476	-0.090	0.006	-6.977	-1.180				
other	-2.728	1.827	-0.048	0.136	-6.314	0.859				
Survivor age	-0.040	0.032	-0.059	0.201	-0.103	0.022				
Survivor pre-existing health condition	0.658	0.574	0.038	0.252	-0.468	1.785				
Survivor hospital stay for COVID-19	0.547	0.660	0.027	0.408	-0.749	1.842				

DISCUSSION

This study fills an important knowledge gap in measuring the impact of COVID-19 on the HRQoL of both the survivors and, importantly, their partners and family members. Health-related quality of life is defined as a person's perception of his/her physical, mental, social and overall well-being (8, 9). Therefore, its assessment embraces a wider view of the impact of COVID- 19.

This study has revealed that the pandemic has a major impact on lives of those who have survived the infection. Pain and discomfort were the most frequently reported problem by COVID-19 survivors, followed by impact on their usual activities, anxiety and depression, affecting females to a greater extent. As the majority of COVID-19 survivors were in paid employment, being physically unwell might have impacted their usual activities or return to work. According to a review on return to work after critical illness (10), globally, a third of previously employed survivors after intensive care stays remained out of work after five years.

Survivors with existing health conditions did not differ significantly from those without such conditions except for mobility. and having an existing health condition was not a significant predictor of impact on the family member/partner's QoL. The survivor's QoL was impacted greatly irrespective of having a pre-existing condition. Hospitalised survivors reported greater impact on mobility, self-care and usual activities compared to those who had not been hospitalised.

The study also revealed a major impact on QoL of the survivors' partners and family members with partners being most impacted. Nearly half of participating partners and family members also reported having had COVID-19. Although there were no significant differences between the family members with COVID-19 and those without across 10 of the 16 QoL items of FROM-16, eating habits, family activities, holiday, sleep, sex-life and work or study were impacted significantly more in those who had had COVID-19. Overall FROM-16 scores were higher for partners and family members with COVID-19 after adjusting for age, gender, relationship to survivor and the overall survivors' EQ-5D scores, thus indicating poorer QoL for family members with COVID-19 than for those without.

Most partners and family members reported being worried and frustrated, many reported sadness, inability to talk to someone and difficulty in caring for their loved ones. This is not surprising in a situation with constant media coverage with emphasis on high daily death rates, the fear of infecting loved ones, stigma due to community or family members blaming survivors for the spread of the illness, isolation of loved ones, inability of a family member to provide support, and prolonged recovery time (11). Such stressors have been implicated in the poor psychological and emotional health of survivors and their family members (11-14).

Family members reported an impact on sexual life as a result of their relative's COVID-19 and this impact was higher in males and in family members who has also contracted COVID-19. Two-thirds of family members were either spouses or partners, who could have experienced these difficulties because of the contagious nature of COVID-19 and because of post survival symptoms. Moreover, physical illness in partners has a significant impact on marital relationships, contributing to marital dissatisfaction and likelihood of later divorce (15). Over half of partners and family members reported impact on holidays and nearly half reported an increase in expenses due to their relative's COVID-19.

One of the key findings of this study is the evidence that in survivors in whom the COVID-19 onset was more than 12 weeks ago, there was still a major persisting impact on QoL across all domains in both survivors and family members. This provides further evidence of the severe impact of post acute COVID-19 ("Long COVID") and "Chronic COVID" (16).

Strengths and Limitations. This study to our knowledge is the first global study to explore the impact of COVID-19 on both survivors and also their family members/partner. Other strengths include the large sample size and use of validated tools to assess QoL impact. The study has demonstrated use of the FROM-16 questionnaire for studying the effects of a pandemic on family members of an infected person.

This study has several limitations. Firstly, it suffers from considerable selection bias as only those COVID-19 survivors and family members who could access the internet and were active on social media completed the online questionnaires, limiting generalisability of the study findings. In addition, the study materials were available only in the English language. Secondly, the study, being cross-sectional, cannot establish causal relationships among the study variables. However, despite these limitations, the study has provided a rapid overview of survivors' and their family members' HRQoL and revealed evidence of the substantial persisting effect on QoL of survivors and a major secondary impact on the lives of partners and family members. This information can be used to inform policymakers about the health needs of these individuals and may encourage the development of tailor-made support services.

Comparison with other studies

Chinese survivors of COVID-19 reported lower HRQoL with significant impact on their physical and psychological health, one month after recovery (17). Our study has shown a major impact not only on the HRQoL of survivors of COVID-19 but also on their partners and family members. This is consistent with the findings of Golics et al. (2, 18) that multiple elements of family members' lives can be affected by a relative's illness including emotional, financial, family relationships, education and work, leisure time, and social activities.

Our study has shown that most (87%) survivors had COVID-19 for more than 4 weeks, and 64% more than 12 weeks indicating that survivors continued to remain unwell for long periods of time, due to post-viral symptoms or ‘long COVID’. This is in contrast to a UK COVID-19 symptom study (19), where only 10% of COVID-19 positive survivors remained unwell at three weeks, and a small proportion for more than three months. An online survey of British doctors in August 2020 revealed that many were being treated for long term COVID-19 symptoms such as chronic fatigue, muscle weakness, loss of sense of smell, and concentration difficulties (20)

In our study 69% COVID-19 survivors reported feelings of anxiety and depression, much higher than the 43.1% reported by Ma Y-F et al. (9) in clinically stable patients with COVID-19. Previous studies of Severe Acute Respiratory Syndrome (SARS) revealed the persistence of depression in patients up to 30 months after discharge from hospital (21, 22).

Several studies have shown the impact of COVID-19 on sleep patterns of survivors, with an increase in prevalence of insomnia (23-25). We do not know whether the sleep patterns of survivors in our study were also impacted, since EQ-5D does not include such an item. However, in our study 69 % of partners and family members experienced problems with sleep, and 32% reported that their sleep was impacted “a lot”.

The total mean domain scores for FROM-16 in this study were 6.12 (Emotional) and 8.88 (Personal and Social Life) which are higher than the mean domain scores reported by Golics et al. (3) (Emotional=5.6; Personal and Social Life=6.7) on the impact of patients’ chronic disease on family members across 26 medical specialties. Another study (4) reported the mean domain scores of family members of patients with cancer as Emotional=4.7 and Personal and Social Life=7.1. In a FROM-16 study on family members of patients with urinary stone disease, family members were not impacted much by their relative's disease, however they reported a slightly greater degree of change in the 'emotional' domain compared with the 'personal and social life' domain (26). This indicates that family members of COVID-19 survivors suffered more than family members of patients with other severe chronic diseases.

Implications for clinicians and policymakers

Our results have shown how the impact of COVID-19 on one family member can have a domino effect on other family members, especially those close to them such as partner, parents and children. It is important to understand the needs of these impacted family members and survivors to ensure the overall wellbeing of the family unit. Based on the findings of this study, policymakers should consider developing and commissioning the following support services for survivors and family members:

Post COVID-19 clinics: Survivors reported pain and discomfort even after 12 weeks of COVID-19, indicating that tailored services to deal with such symptoms are important to help survivors suffering with long term sequelae. Survivors with post-COVID-19 complications should be heard and treated. Although such clinics have been started in a few countries, there is a considerable need for such initiatives globally.

Needs-based mental health counselling: Most family members and survivors reported being depressed and worried. It is imperative to further develop care services to ensure the mental wellbeing of survivors and their family members.

Physical activity and rehabilitation services: Most survivors have reported pain and discomfort and an inability to do their normal activities. Rehabilitation clinics could provide emotional and physical support to physically and emotionally drained survivors and their family members to enable their return to normal routines.

Social support services: Patients with COVID-19 are from diverse backgrounds and therefore will benefit from culturally and socially appropriate support. Financial assistance is particularly important for those who do not have health insurance to cover COVID-19 expenses.

Patient support groups/local support groups for COVID-19 survivors and family members: Local support groups could be used in primary care settings and can help by significantly combating isolation and the disability the study has identified that occurs in COVID-19 survivors and their family members/partners. This could in turn have health economic benefits by possibly reducing long-term utilisation of mental health services. Similar approaches have been successful, for example in supporting people with myalgic encephalitis.

Unanswered questions and future research

Although this study provided an overview of the impact of COVID-19 on survivors' partners and family members, it was not designed to identify causal relationship. Future longitudinal studies are needed to understand the long-term impact of COVID-19. We were unable to measure the impact of COVID-19 on sleep and sex-life of survivors, future studies should measure such impacts.

CONCLUSION

Survivors of COVID-19 report a major persisting impact on their QoL with many feeling unwell beyond 12 weeks. This indicates a demand for a holistic support system that is sensitive to their needs. Moreover, the QoL of partners and family members is also severely impacted, demonstrating the importance of investigating disease impact on family QoL. The establishment of services to provide support to family members of survivors and patients in general is therefore a key consideration in the future management of COVID-19.

Acknowledgements

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Competing interests: All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no support from any organisation for the submitted work; RS and SJN declared no competing interest, AYF and SS are joint copyright owners of Family Reported Outcome Measure (FROM-16). JRI reports personal fees from UCB Pharma, personal fees from Novartis, personal fees from Boehringer Ingelheim, personal fees from Kymera Therapeutics, personal fees from Viela Bio, personal fees from UpToDate, personal fees from Editor of British Journal of Dermatology, outside the submitted work; in addition, JRI is co-copyright holder of the Hidradenitis Suppurativa Quality of Life (HiSQOL) score. FMA reports grants and personal fees from Janssen, personal fees from Abbvie, personal fees from Lilly Pharmaceuticals, personal fees from L'Oreal, personal fees from LEO Pharmaceuticals, personal fees from UCB, outside the submitted work.

Author contributions: RS primarily carried out the study. wrote first drafts and revised all documentation. SS and AYF equally contributed to the design and supervision of the study and revised all study documentation and the manuscript. FMA, JRI and SJN provided advice during the study and helped revise study documentation. FMA, JRI and SJN reviewed the manuscript. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

Public and Patient Involvement (PPI): Twenty members of the public, including some work colleagues, participated in the pilot study. Some had experience of having COVID-19 patient in their family. The study sociodemographic questions were extensively modified following the outcome of the pilot study. The 'patients and family member group' consisting of two patients and one family member, were involved as study research partners. This group was involved in reviewing the study protocol, other related documents and the manuscript.

Ethical approval: Ethics approval was granted by the Cardiff University School of Medicine Research Ethics Committee (SMREC 20/60).

Data sharing: This paper does not report a trial. If requested, we are happy to share our data.

Transparency statement: The lead author RS affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Dissemination to participants and related patient and public communities: The summary of the results will also be disseminated by social media using the same methods as used for recruiting participants and made accessible to public and patients through the Cardiff University FROM-16 website page

Figure legends

Figure1 COVID-19 survivor response to EQ-5D-3L (n=735)

Figure 2 Partner and family member response to FROM-16 items (n=735)

Figure 3 Mean scores of individual FROM-16 items for family members diagnosed with COVID-19 and those with no history of COVID-19

Figure 4 Scatter plot showing positive relationship between COVID-19 survivors' EQ-5D and family members' FROM-16 scores

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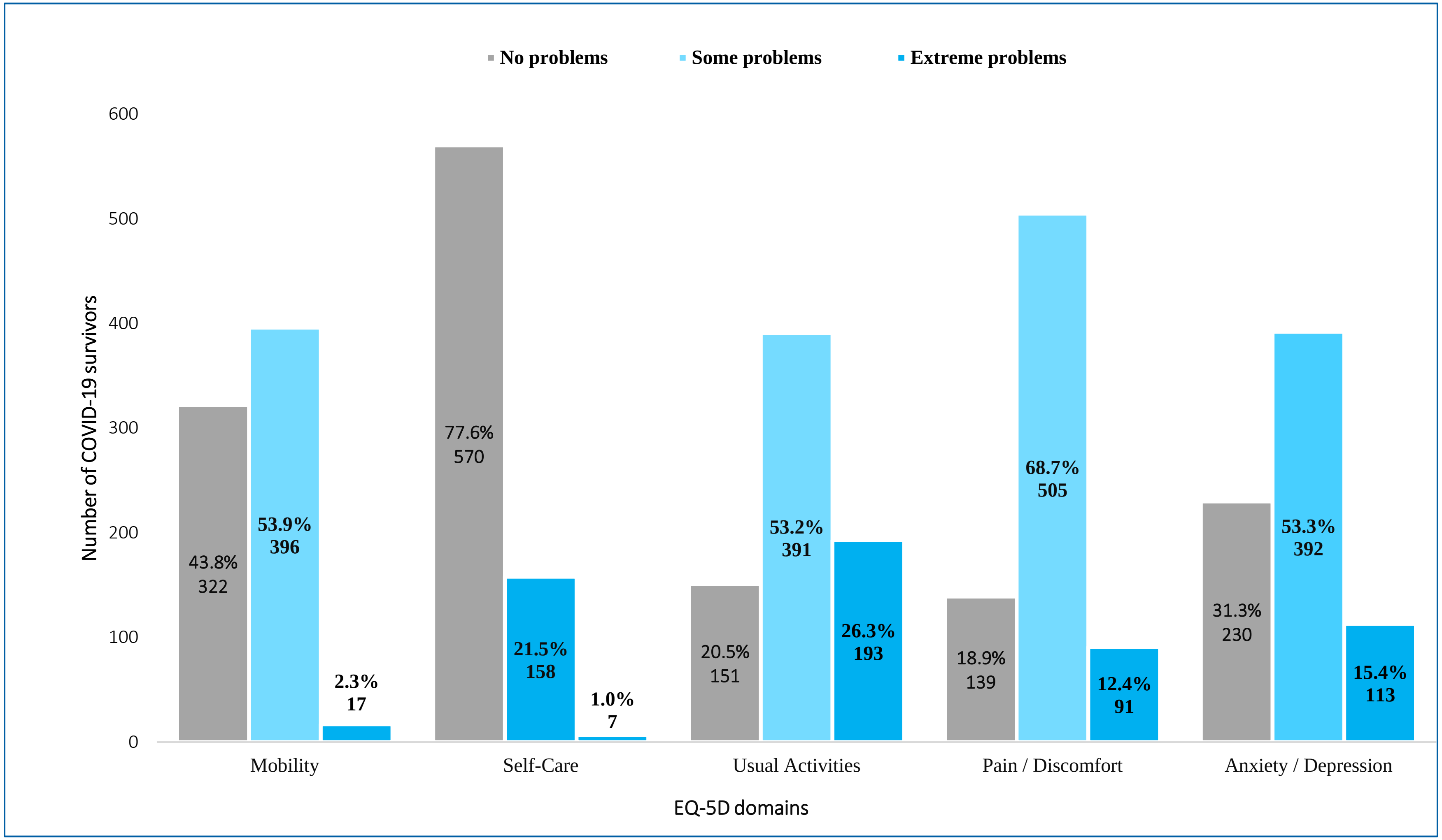
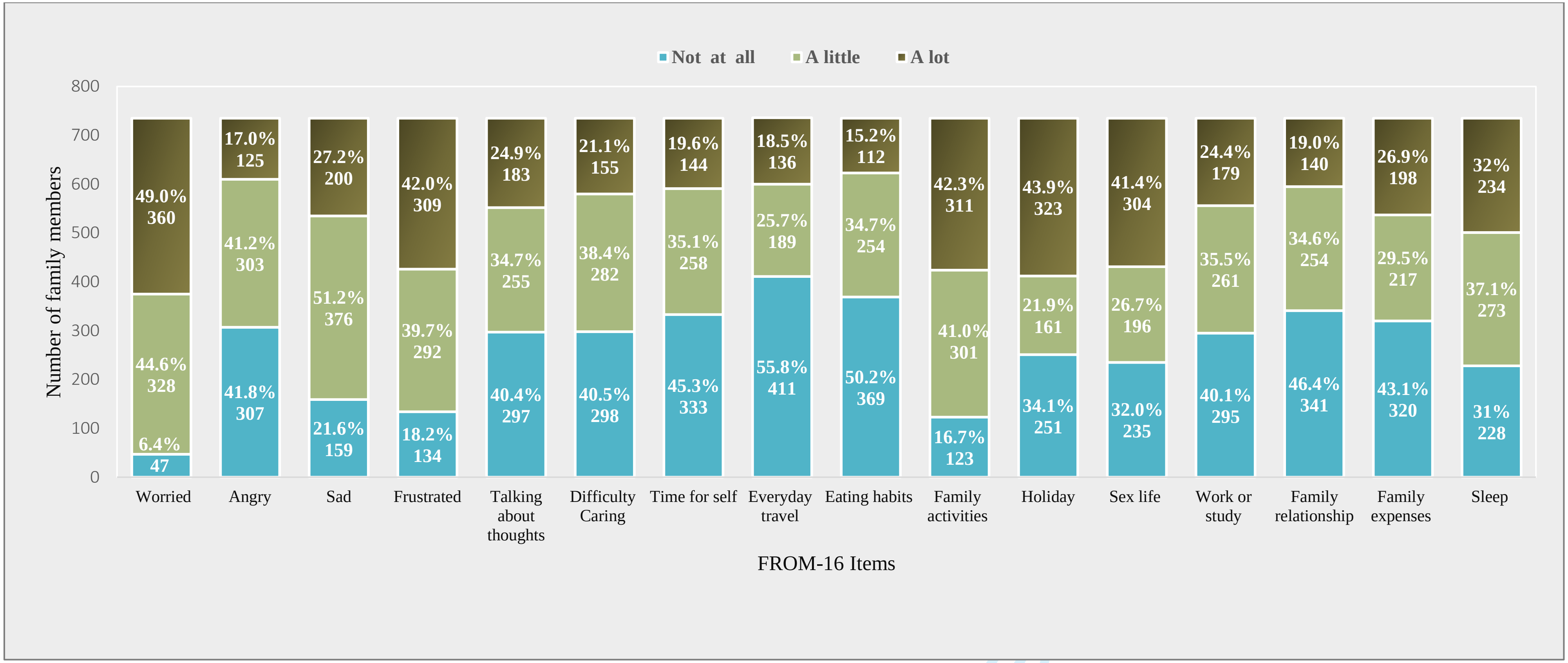
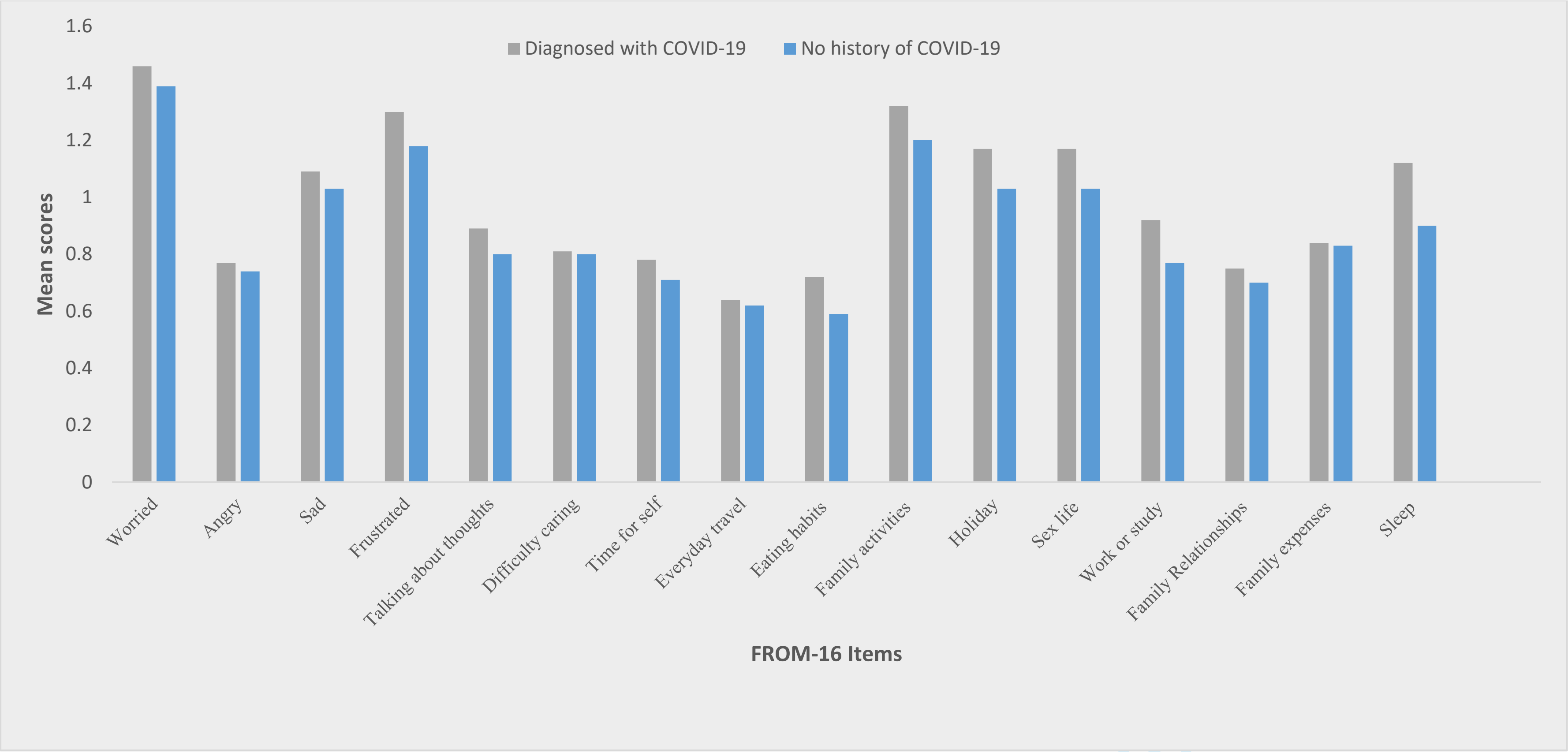
Figure1 COVID-19 survivor response to EQ-5D-3L (n=735)




Not at all
A little
A lot
Number of family members
800
700
600
500
400
300
200
100
0
Worried: 6.4% 47; 44.6% 328; 49.0% 360
Angry: 41.8% 307; 41.2% 303; 17.0% 125
Sad: 21.6% 159; 51.2% 376; 27.2% 200
Frustrated: 18.2% 134; 39.7% 292; 42.0% 309
Talking about thoughts: 40.4% 297; 34.7% 255; 24.9% 183
Difficulty Caring: 40.5% 298; 38.4% 282; 21.1% 155
Time for self: 45.3% 333; 35.1% 258; 19.6% 144
Everyday travel: 55.8% 411; 25.7% 189; 18.5% 136
Eating habits: 50.2% 369; 34.7% 254; 15.2% 112
Family activities: 16.7% 123; 41.0% 301; 42.3% 311
Holiday: 34.1% 251; 21.9% 161; 43.9% 323
Sex life: 32.0% 235; 26.7% 196; 41.4% 304
Work or study: 40.1% 295; 35.5% 261; 24.4% 179
Family relationship: 46.4% 341; 34.6% 254; 19.0% 140
Family expenses: 43.1% 320; 29.5% 217; 26.9% 198
Sleep: 31% 228; 37.1% 273; 32% 234
FROM-16 Items


Diagnosed with COVID-19
No history of COVID-19
Mean scores
1.6
1.4
1.2
1
0.8
0.6
0.4
0.2
0
Worried
Angry
Sad
Frustrated
Talking about thoughts
Difficulty caring
Time for self
Everyday travel
Eating habits
Family activities
Holiday
Sex life
Work or study
Family Relationships
Family expenses
Sleep
FROM-16 Items

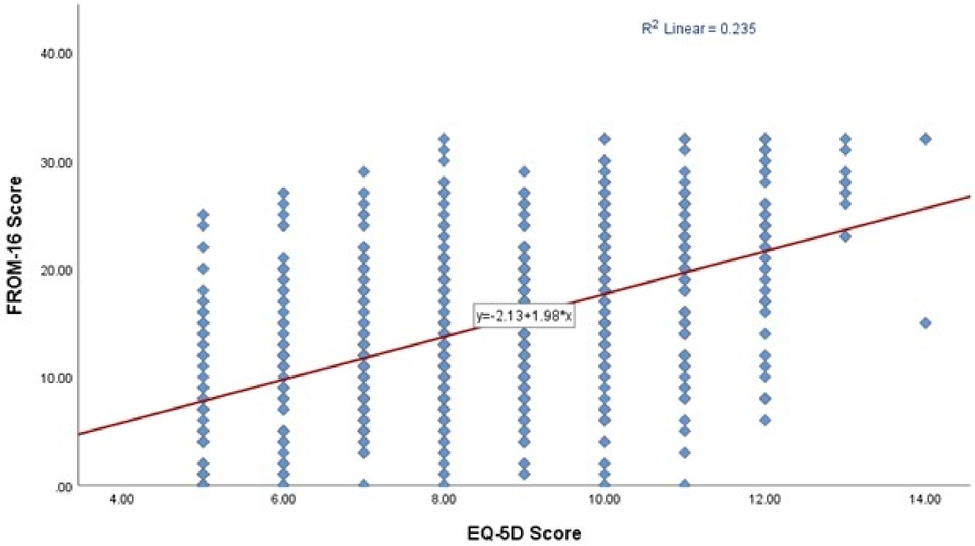


Figure 3 Mean scores of individual FROM-16 items for family members diagnosed with COVID-19 and those with no history of COVID-19

168x99mm (96 x 96 DPI)

Lay summary

Impact of COVID-19 on Quality of Life of Survivors and their Partners and Family members

Much research has been published about COVID-19, but there is very little information concerning the impact on the lives of partners and family members of those infected with COVID-19.

We asked people who had had COVID-19 and their partners and family members to complete an online survey using social media, such as Facebook and Twitter, from June to August 2020 to understand the impact of COVID-19. 735 survivors, their partners and family members from across Europe, North America and rest of the world took part. We found that the quality of life of both survivors, their partners and family members were greatly affected by COVID-19.

Most survivors of COVID-19 who took part in the survey continued to experience a major impact on their quality of life beyond four weeks of having had COVID-19 (637/735). Some of these people may have had the syndrome now known as 'Long COVID'. Most COVID-19 survivors reported pain and discomfort, inability to do their usual activities, anxiety and depression. Survivors who had been hospitalised for COVID-19 reported a greater impact on quality of life while those who had other health conditions such as diabetes, heart disease or breathing problems reported experiencing difficulties in walking and moving around.

Partners and family members of COVID-19 survivors were also severely affected. Most partners and family members felt worried and frustrated, experienced a huge impact on their family activities, with many having problems with their sleep and sex-life. Nearly half of the partners and family members who responded had also developed COVID-19. Although, there was no significant differences between the family members with COVID-19 and those without it across 10 of the 16 Quality of life areas, eating habits, family activities, holiday, sleep, sex-life, work and study were more impacted in partner and family member with COVID-19.

These findings suggest the need for a holistic support system sensitive to the needs of COVID-19 survivors and their family members. The major continuing impact on the quality of life of survivors of COVID-19 and their family members needs to be understood by health care workers and services developed to help people to get back to their pre-COVID-19 lives.

Section/Topic	Item #	Recommendation	Page No	Relevant text from the manuscript
Title and abstract	1	(*a*) Indicate the study’s design with a commonly used term in the title or the abstract	2	Abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2	Abstract page 1
Introduction				
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3	Introduction- paragraph 1, 2
Objectives	3	State specific objectives, including any prespecified hypotheses	4	Introduction- paragraph 3
Methods				
Study design	4	Present key elements of study design early in the paper	4, 5	Methods
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4-5	Methods-setting/ participants / procedure
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5	Method-procedure
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6	Methods -outcome /exposure/Covariates/missing data
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6	Methods-Measurements tools
Bias	9	Describe any efforts to address potential sources of bias	*7, 14-15*	Methods and Regression
Study size	10	Explain how the study size was arrived at		Study Size = Exploratory
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	7	Statistical analysis
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	7	
		(*b*) Describe any methods used to examine subgroups and interactions	7-17	Statistical analysis and Tables 1-7
		(*c*) Explain how missing data were addressed	7	There were no missing data
		(*d*) If applicable, describe analytical methods taking account of sampling strategy		Exploratory
		(*e*) Describe any sensitivity analyses		Not applicable

Results				
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7	Results section
		(b) Give reasons for non-participation at each stage		Not applicable
		(c) Consider use of a flow diagram		Not applicable
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7-8	Table 1 descriptive analysis
		(b) Indicate number of participants with missing data for each variable of interest		NA (no missing data)
Outcome data	15*	Report numbers of outcome events or summary measures	7	Results and Tables/Figures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included	7-17	Results section-Table 3, 4 and 5. Multiple regression Tables 6 and 7
		(*b*) Report category boundaries when continuous variables were categorised		Not Applicable
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period		Not Applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	10-13	Results – Sub group analysis-male /female; hospitalise for COVID-19/not hospitalised ; Pre-existing health condition / No pre-existing health condition; partner and Family member 's with COVID / Partner and family not having COVID Tables 3 and 4
Discussion				
Key results	18	Summarise key results with reference to study objectives	18-19	16-17
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	20	Strengths and Limitation section
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	20-21	Strengths and limitation / comparison with other studies

Generalisability	21	Discuss the generalisability (external validity) of the study results	20	Strengths and limitations section
Other information				
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based.	24	Funding section

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Measuring the impact of COVID-19 on the quality of life of the survivors, partners and family members: A cross-sectional international online survey

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Primary Subject Heading:	Public health
Secondary Subject Heading:	Infectious diseases
Keywords:	COVID-19, Public health < INFECTIOUS DISEASES, Infection control < INFECTIOUS DISEASES

Measuring the impact of COVID-19 on the quality of life of the survivors, partners and family members: A cross-sectional international online survey

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Word count: 4,835

ABSTRACT

Objective:

This study aimed to measure the impact of COVID-19 on the quality of life (QoL) of survivors and their partners and family members.

Design and Setting:

A prospective cross-sectional global online survey using social media.

Participants:

COVID-19 patients and partners or family members (age ≥18 years).

Intervention:

Online survey from June to August 2020.

Main outcome measure:

The EQ-5D-3L to measure the QoL of survivors of COVID-19, and the Family Reported Outcome Measure (FROM-16) to assess the impact on their partner/family member's QoL.

Results:

The survey was completed by 735 COVID-19 survivors (mean age=48 years; females=563) at a mean of 12.8 weeks after diagnosis and by 571 partners and 164 family members (n=735; mean age=47 years; females=246) from Europe (50.6%), North America (38.5%) and rest of the world (10.9%). The EQ-5D mean score for COVID-19 survivors was 8.65 (SD=1.9, median=9; range=6-14). 81.1% (596/735) reported pain and discomfort, 79.5% (584/735) problems with usual activities, 68.7% (505/735) anxiety and depression and 56.2% (413/735) problems with mobility. Hospitalised survivors(20 %, n=148) and survivors with existing health conditions (30%, n=227) reported significantly more problems with mobility and usual activities ($p<0.05$), with hospitalised also experiencing more impact on self-care ($p\leq0.001$).

Among 735 partners and family members, the mean FROM-16 score (maximum score = highest impact =32) was 15 (median=15, range=0-32). 93.6% (688/735) reported being worried, 81.7% (601/735) frustrated, 78.4% (676/735) sad, 83.3 % (612/735) reported impact on their family activities, 68.9% (507/735) on sleep and 68.1% (500/735) on their sex life.

Conclusion:

COVID-19 survivors reported a major persisting impact on their physical and psychosocial health. The lives of their partners and other family members were also severely affected. There is a need for a holistic support system sensitive to the needs of COVID-19 survivors and their family members who experience a major "secondary burden".

Keywords

COVID-19; Long COVID, family impact; partner impact; patient impact; EQ-5D; quality of life; FROM-16; Family- Reported Outcome Measure.

Strengths and Limitations of this study

- This study provides evidence of the impact on quality of life (QoL) of 'Long COVID' in survivors of COVID-19.
- This study fills an important knowledge gap in measuring the impact of survivors' COVID-19 on the QoL of partners and other family members.
- Large sample size, heterogenous population and use of validated tools to assess QoL impact
- The study was open to COVID survivors and their family members internationally, but only those active on social media who could read and understand English completed the survey.
- Causal relationships cannot be established among the study variables as the study was cross-sectional.

INTRODUCTION

The COVID-19 pandemic is causing profound changes across the world, but there is little information on its physical and psychosocial impact on survivors and their families. Despite the need (1) for information on the lived experience of infected individuals and their family members, there are only sparse data available.

It is important to ascertain COVID-19's immediate and persisting (Long COVID) impact on those affected and on their families in order to aid healthcare workers and government agencies to better support them. The understanding of how a person's health condition impacts the quality of life (QoL) of other family members has increased over the last decade (2).

The aim of this study was to assess the impact of COVID-19 on survivors and their family members based on their lived experience of COVID-19 using validated QoL instruments administered using online social media platforms.

METHODS

Settings and participants

This was a prospective cross-sectional global online survey, using an anonymous online questionnaire. The survey was carried out using https://www.onlinesurveys.ac.uk/ on a Jisc platform (3). The survey was distributed through social media platforms including Facebook, Twitter, LinkedIn, WhatsApp and Reddit.

Procedure

Ethics approval was granted by the Cardiff University School of Medicine Research Ethics Committee (SMREC 20/60). Study participants were provided with information about the study via a link in the survey to a "Participant Information Sheet" where they were informed that participation was voluntary and their data would remain anonymous. Those who decided to take part gave informed consent at the beginning of the survey. Data collection took place from 30th May to 30th August 2020.

The study was only open to individuals who were diagnosed with COVID-19 and their family member or partner, adults aged 18 years or above who could read and understand English, and who were able to give written consent and complete the questionnaire using an electronic device. Participants were excluded if they had not had COVID-19 or if they were less than 18 years of age.

Survey development

The survey included two QoL questionnaires: EuroQol group 5 Dimensions 3 level (EQ-5D-3L) and Family Reported Outcome Measure (FROM-16). There were additional socio-demographic questions such as responder’s age, gender and country of residence (Table 1). A pre-test draft survey was piloted during May 2020 in 20 individuals without COVID-19 across several countries including the UK, India, and the UAE. Views were also sought from the study research partners, a patient and two family members. The survey questions were revised based on the collective feedback.

Patient and public involvement

Two patients and one family member were involved as integral study research partners, one of whom (SJN) is a co-author. They were involved in reviewing the study protocol, drafting the survey, reviewing the manuscript and providing suggestions from the patient and family perspective.

Survey structure

The survey had two sections. Section one was completed by the COVID-19 survivor. Each survivor provided basic demographic details and provided EQ-5D-3L responses. Section two was completed by the partner or a family member of the survivor who provided basic demographic details and completed FROM-16. The survey did not specify whether this should be someone the patient lives with or whether it could be any close relation; however, the family member of the COVID-19 survivor was asked to specify their relationship to the patient.

Measurement tools

The EQ-5D-3 L is a self-reported generic health-related QoL (HRQoL) instrument that specifically addresses health status (4). It consists of five questions on mobility, self-care, usual activities, pain and discomfort, and anxiety and depression with 3-point response categories (1= no problems, 2= some problems and 3= serious or extreme problems). The EQ-VAS component of EQ-5D-3L asks respondents to rate their overall health status from 0 (worst imaginable health) to 100 (best imaginable health). In this study, for simplicity throughout this manuscript, we refer to EQ-5D-3L as 'EQ-5D'.

The FROM-16 measures the impact of a patient's disease on the QoL of a family member or partner of a patient (5). The FROM-16 comprises 16 items with 3-point response options for each: not at all (scoring 0), a little (1) and a lot (2), with a total score range of 0 - 32. The higher the score, the greater the negative impact on the family member's QoL. The 16 items are divided into two domains: Emotional (six items, maximum score12) and Personal and Social Life (ten items, maximum score 20). The FROM-16 has proven psychometric properties, a rapid completion time of two minutes (5) and translations are available in several languages (6). A generic measure, the FROM-16 has been validated across all areas of medicine (5-7) and is therefore suitable for measuring the impact of

COVID-19 on the partner and family members of those affected. As it is a generic measure, data generated can be compared with data from other medical conditions.

Outcome: The impact of COVID-19 on the quality of life of survivors and their partners and family members.

Exposure: COVID-19 infection of the participant or of the family member.

Covariates: The covariates included hospital stay due to COVID-19 infection, existing health condition of survivors, weeks since first had COVID-19, partners and family members diagnosed with COVID-19, family members' relationship to survivors, country of residence, age and sex of family members and survivors. All the covariates, including hospitalisation, existing conditions and weeks since first had COVID-19 were based on self-report.

Missing data: There were no missing data, but two responses were ambiguous for one of the variables (EQ-VAS) and were excluded from the analysis.

Statistical analysis

Descriptive statistics (i.e. mean, standard deviation, median, inter-quartile range) were performed for all variables. The Shapiro–Wilk test was used to examine normal distribution of continuous variables. The required assumptions for normal distribution were not met. Consequently, data analysis employed non-parametric statistical method. Both the EQ-5D-3L and the FROM-16 scores were treated in the analysis as dependent variables. The EQ-VAS score was calculated separately since it represents a different construct. To determine differences between groups defined by each outcome, chi-square tests (when appropriate, Fisher's exact tests) and Mann-Whitney U tests were computed. These bivariate comparisons were based on COVID-19 survivor's characteristics (gender, existing health condition, and hospitalisation) and family member characteristics (gender and whether diagnosed with COVID-19). Spearman's rank correlation coefficient and multiple regression analysis were conducted to understand the effect of independent variables (i.e. predictors: survivor age, existing health condition, hospital stay for COVID-19, weeks since first had COVID-19, survivor gender) on the EQ-5D outcomes. Similarly, these analyses were conducted to understand the effect of independent variables (EQ-5D score, age family member, weeks since first had COVID-19, family member gender, whether family member also had COVID-19, relationship to survivor, survivor age, survivor existing health condition, survivor hospital stay for COVID-19) on the FROM-16 outcomes. Statistical Product and Service Solutions SPSS® (version 25) was used and the probability of type I error was set at $p < 0.05$.

RESULTS

Sociodemographic characteristics of the study participants

A total of 1,254 respondents consented to participate in the survey: 765 completed both sections. Thirty responses were excluded as the respondents were below the age of 18 years. The final analysis included 735 COVID-19 survivors and their family members/partner from Europe (50.6%), North America (38.5%) and the rest of the world (10.9%) (Table 1).

Table 1 Sociodemographic characteristics of the study participants

Variables	Categories	N (%) or N(SD)
COVID-19 Survivors (n=735)		
Gender	Male	172 (23.4%)
	Female	563 (76.6%)
Age (years)	Mean (SD)	47.77 (11.656)
	Median	48.00
	Range	19-85
	Range (IQR)	19-85 (16)
Weeks since first had COVID-19	Mean (SD)	12.76 (6.104)
	Median	13.00
	Range	1-36
	Range (IQR)	1-36 (8)
	≥4 weeks	98 (13.3%)
	5-11 weeks	170 (23.1%)
	≥12 weeks	467 (63.5%)
Occupation	Unemployed	19 (2.6%)
	In paid work	538 (73.2%)
	In education or training	26 (3.5%)
	In unpaid work	7 (1%)
	Work in the home/manage the family	60 (8.2%)
	Retired	66 (9%)

	Rather not say	19 (2.6%)
Existing health conditions	No	508 (69.1%)
	Yes	227 (30.9%)
Hospitalised for COVID-19	No	587 (79.9%)
	Yes	148 (20.1%)
Regions	Europe	372 (50.6%)
	North America	283 (38.5%)
	Rest of the World	80 (10.9%)
Family members (N=735)		
Gender	Male	489 (66.5%)
	Female	246 (33.5%)
Age (years)	Mean (SD)	47.43 (13.582)
	Median	48.00
	Range	18-87
Occupation	Unemployed	42 (5.7%)
	In paid work	530 (72.1%)
	In education or training	29 (3.9%)
	In unpaid work	18 (2.4%)
	Retired	95 (12.9%)
	Rather not say	21 (2.9%)
Relationship to the person affected with COVID-19	Spouse/Partner	571 (77.7%)
	Parents	48 (6.5%)
	Son/Daughter	77 (10.5%)
	Brother/Sister	24 (3.3%)
	Other	15 (2%)
Diagnosed with COVID-19	No	380 (51.7%)
	Yes	355 (48.3%)

Of the 735 COVID-19 survivors, 76.6% were females (mean and median age=48 years) and 73.3% were in paid employment. The mean time since COVID-19 symptoms started was 12.8 weeks (median=13 weeks). In 86.6% (n=637) > 4 weeks had elapsed since COVID-19 symptoms started and in 63.5% (n=467) >12 weeks had elapsed. Of the family members (mean age=48 years, median=47 years), 66.5 % were male and 72.1% were in paid employment. Most of the family members were partners (77.7%), followed by sons and daughters (10.5%) and parents (6.5%). In addition, 48.3 % of the family members had also contracted COVID-19 (Table 1).

Quality of life impact of COVID-19 on survivors

The EQ-5D mean score was 1.73 (SD=0.39) with the ‘usual activities’ item scoring the highest (mean=2.06, max 3) followed by pain/discomfort (1.93) and anxiety/depression (1.84). The mean score of the visual analogue part of EQ-5D was 55 (SD=22.94) (Table 2).

Table 2 Mean scores of EQ-5D and FROM-16 (n=735)

Scale	Mean (SD)	Median (interquartile range)	Range
EQ-5D-3L domains			
Overall	8.65 (1.97)	9 (3)	6-14
Mobility	1.59 (0.54)	2 (1)	1-3
Self-Care	1.23 (0.45)	1 (0)	1-3
Usual Activities	**2.06** (0.68)	2 (1)	1-3
Pain / Discomfort	**1.93** (0.56)	2 (0)	1-3
Anxiety / Depression	**1.84** (0.67)	2 (1)	1-3
EQ-VAS n(733)	55.83 (22.94)	60(35)	3-100
FROM-16			
Overall	15.00 (8.05)	15 (13)	0-32
Emotional Domain	6.12 (3.23)	6.0 (5)	0-12
Worried	**1.43** (0.61)	1 (1)	0-3
Angry	0.75 (0.73)	1(1)	0-3
Sad	**1.05** (0.70)	1 (1)	0-3
Frustrated	**1.24** (0.74)	1 (1)	0-3
Talking about thoughts	0.84 (0.79)	1 (1)	0-3
Difficulty caring	0.81 (0.76)	1 (1)	0-3
Personal and Social Domain	8.88 (5.51)	9.0 (9)	0-20
Time for self	0.74 (0.76)	1 (1)	0-3
Everyday travel	0.63 (0.78)	0 (1)	0-3
Eating habits	0.65 (0.73)	0 (1)	0-3
Family activities	**1.26** (0.73)	1 (1)	0-3
Holiday	**1.10** (0.88)	1 (2)	0-3
Sex life	**1.09** (0.85)	1 (2)	0-3
Work or study	0.84 (0.79)	1 (1)	0-3
Family Relationship	0.73 (0.76)	1 (1)	0-3
Family expenses	0.83 (0.82)	1 (2)	0-3
Sleep	**1.01** (0.79)	1(2)	0-3

Of the five dimensions of EQ-5D, ‘pain and discomfort’ was the impact most frequently reported (81.1%; 68.7 % some problems and 12.4% extreme problems), followed by usual activities (79.5%; 53.2% and 26.3%) and anxiety and depression (68.7%; 53.3% and 15.4%) (Figure 1). There was a significant gender difference for ‘mobility’ and for ‘pain and discomfort’ ($p \leq 0.05$) with females being more impacted than males (Table 3).

Although existing health conditions were self-reported and severity was not stated, survivors with existing health conditions did not appear to differ from those without such conditions except for mobility $p \leq 0.05$) (Table 3). Having an existing health condition was not a clear predictor of impact on the family member/partner’s QoL.. There was a significant difference between the survivors who had been hospitalised for COVID-19 (20%) and those who had not, with the hospitalised survivors being more severely affected across mobility, self-care ($p \leq 0.001$) and usual activities ($p \leq 0.02$) (Table 3).

There were significant differences in EQ-5D mean scores between survivors with respect to weeks since first had COVID-19 ($p<0.001$). Mean EQ-5D scores of survivors having COVID-19 symptoms for up to 4 weeks was 8.03 (SD=1.97), 5-11 weeks was 8.3 (SD=2.13) and 12 weeks and above was 8.9 (SD=1.86).

, Table 3 Comparisons † of EQ-5D scores for gender, existing health condition and hospitalisation

EQ-5D domain	Gender Mean score Male (n=172)	 Female (n=563)	p-value**	Existing health condition Mean score Yes (n=227)	 No (n=508)	p-value**	Hospitalised for COVID-19 Mean score Yes (n=148)	 No (n=587)	p-value**
Overall	8.33	8.74	**0.036**	8.89	8.54	**0.012**	9.17	8.51	**0.001**
Mobility	1.51	1.61	**0.037**	1.67	1.55	**0.006**	1.75	1.54	**0.0001**
Self-Care	1.22	1.24	0.602	1.28	1.21	0.053	1.36	1.20	**0.0001**
Usual Activities	1.97	2.08	0.065	2.14	2.02	**0.034**	2.19	2.02	**0.009**
Pain / Discomfort	1.82	1.97	**0.002**	1.93	1.94	0.989	1.99	1.92	0.141
Anxiety / Depression	1.81	1.85	0.611	1.88	1.82	0.289	1.88	1.83	0.427

† Mann Whitney U test

**p values were calculated using mean rank scores but mean scores are presented here for ease of understanding.

Quality of life impact of COVID-19 on family members

The mean FROM-16 score was 15, reflecting the extent of the impact of the survivors' COVID-19 on the HRQoL of their family members (Table 2). The mean score of each of the 16 items is given in Table 2 with 'Feeling worried' scoring highest (1.46) followed by family activities, frustration, holiday, and sex life (1.26, 1.24, 1.10 and 1.09, respectively) (Table 2). Of the FROM-16 items, the feeling of being worried was most frequently reported (93.6%; 44.6% a little, 49% a lot), followed by family activities (83.3%; 41% , 42.3%), feeling of frustration (81.7%; 39.7% , 42%), feeling sad (78.4%; 51.2%, 27.2 %), sleep (68.9%; 37.1%, 31.8 %) and sex life (68.1%; 26.7%, 41.4%) (Figure 2).

There was a significant gender difference among family members, with females feeling more sad, experiencing more impact on everyday travel ($p \leq 0.01$) and on their sleep $p \leq 0.05$). The impact on sex life was experienced significantly more by males than females ($p \leq 0.001$) (Table 4).

Table 4 Comparisons†of FROM-16 scores for gender and for whether diagnosed with COVID-19 (n=735)

FROM-16 Items	Gender Mean score Male (n=489)	Female (n=246)	p-value**	Diagnosed with COVID-19 Mean score Yes (n=355)	No (n=380)	p-value**
Overall	14.81	15.36	0.401	15.74	14.32	**0.017**
Worried	1.40	1.48	0.068	1.46	1.39	0.135
Angry	0.73	0.79	0.332	0.77	0.74	0.519
Sad	1.00	1.16	**0.004**	1.09	1.03	0.225
Frustrated	1.23	1.26	0.569	1.30	1.18	0.054
Talking about thoughts	0.83	0.87	0.651	0.89	0.80	0.132
Difficulty caring	0.79	0.85	0.324	0.81	0.80	0.847
Time for self	0.70	0.83	**0.036**	0.78	0.71	0.164
Everyday travel	0.58	0.72	**0.048**	0.64	0.62	0.874
Eating habits	0.64	0.67	0.565	0.72	0.59	**0.015**
Family activities	1.28	1.21	0.144	1.32	1.20	**0.041**
Holiday	1.10	1.10	0.992	1.17	1.03	**0.030**
Sex life	1.22	0.84	**0.000**	1.17	1.03	**0.035**
Work or study	0.83	0.87	0.485	0.92	0.77	**0.013**
Family relationships	0.69	0.79	0.109	0.75	0.70	0.281
Family expenses	0.81	0.87	0.367	0.84	0.83	0.759
Sleep	0.98	1.07	0.138	1.12	0.90	**0.000**

†Mann Whitney U test;
**p values were calculated using mean rank scores but mean scores are presented here for ease of understanding.

Those with a COVID-19 history experienced a greater impact on eating habits, work and study, family activities, holiday ($p \leq 0.05$), sex life and sleep ($p \leq 0.001$). There were no significant differences for the remaining 10 items of FROM-16 (Table 4).

There were significant differences in FROM-16 mean scores between family members of survivors with respect to onset of COVID-19 symptoms ($p < 0.01$). Mean FROM-16 scores of family members of survivors having COVID-19 symptoms for up to 4 weeks was 16.11 (SD=7.35), 5-11 weeks was 13.31 (SD=7.77) and 12 weeks and above was 15.38 (SD=8.21).

Relationship between the quality of life of survivors and their family members

There were significant positive correlations between the EQ-5D score and the survivors' gender, hospital stay, existing health condition and weeks since first had COVID-19 ($p < 0.05$, $p < 0.001$) (Table 5).

There was a significant positive association between the family members' FROM-16 scores and the survivors' EQ-5D scores ($p < 0.001$) (Tables 5) and a significant negative association between FROM-16 scores and the family members' age, survivors' age and EQ-VAS scores ($p < 0.05$).

The EQ-VAS scores showed a significant inverse relationship with EQ-5D ($p < 0.01$). However, other variables such as hospital stay, existing health condition and gender (being female) were associated with lower EQ-VAS scores ($p < 0.05$), that is, lower health status (Table 5).

Can quality of life predict outcomes?

The results of multiple regression analyses indicated that survivors' demographics, weeks since first had COVID-19 and hospital stay were significant predictors of the extent of impact on QoL of the survivor ($p=0.001$) while the survivors' existing health condition was not a predictor (Tables 6). Inclusion of variables such as EQ-5D scores, family members' COVID-19 history, family members' gender and relationship to the survivor in the model predicted family reported outcomes ($p=0.001$) while family members' age, survivors' age, weeks since first had COVID-19, existing health condition and hospital stay were not significant predictors of QoL of family members (Table 7). The multiple regression analyses confirmed that the QoL of family members/partner was more impacted than survivors, female family members were affected more than males, family members with a history of COVID-19 were affected more than those without and partners were affected substantially more than those of other relationships. In addition, the model predicted that younger survivors' functional behaviour (both physical and psychosocial) was more impacted by COVID-19.

Table 5 Correlation[†] matrix demonstrating the relationships between EQ-5D, FROM-16 and the participant demographics (n=735)

		1	2	3	4	5	6	7	8	9	10
1	EQ-5D score	1									
2	FROM-16 score	0.467**	1								
3	EQ-VAS (n=733)	-0.591**	-0.346**	1							
4	COVID-19 survivor age (years)	-0.020	-0.118*	-0.075	1						
5	COVID-19 survivor gender	0.077*	-0.024	-0.102*	0.064	1					
6	Stayed in a hospital for COVID-19	0.127*	0.073	-0.097*	0.143*	-0.091*	1				
7	Survivor existing health condition	0.093*	0.066	-0.104*	0.201**	0.036	0.134*	1			
8	Weeks since first had COVID-19	0.164*	0.029	-0.218	0.158*	0.032	0.097*	0.042	1		
9	Family member age (years)	-0.015	-0.077	-0.025	0.535**	0.066	0.034	0.145*	0.108*	1	
10	Family member gender	-0.030	0.031	0.032	-0.008	-0.507**	0.097*	0.050	-0.034	-0.113*	1

[†] Spearman's Rank; *p ≤ 0.05, **p ≤ 0.01, 2-tailed.

The numbers 1-10 in the horizontal heading bar represent the same numbers as given in the left-hand column. Each number refers to the variable described next to it.

Table 6 Summary of survivors' characteristics predicting EQ-5D scores[*] (n=735)

	Unstandardised coefficients		Standardised coefficients		95% confidence interval levels for B					
Predictor	*B*	*Std. Error*	*Beta*	*p-value*	*Lower level*	*Upper Level*	*R^2*	*Adjusted R^2*	*F-test*	*p-value*
							0.058	0.051	8.907	0.0001
Survivor Age	-0.013	0.006	-0.076	0.043	-0.025	0.000				
Existing health condition	0.298	0.157	0.070	0.059	-0.011	0.607				
Hospital stay for COVID-19	0.644	0.181	0.131	0.0001	0.288	1.001				
Weeks since first had COVID- 19	0.050	0.012	0.154	0.0001	0.027	0.073				
Survivor gender	-0.471	0.169	-0.101	0.005	-0.802	-0.139				

[*] Multiple regression; B=the slope of the line between the predictor variable and the dependent variable – the larger the number, the more spread out the points are from the regression line; F-test=degree of the linear regression model fitting the data; R^2 = how well the model fits the data; Males=1 and females =0; females are the reference group.

Table 7 Summary of family member/partner characteristics predicting FROM-16 scores* (n=753)

	Unstandardised coefficients		Standardised coefficients		95% confidence interval levels for *B*					
Predictor	*B*	*Std. Error*	*Beta*	*p-value*	*Lower Level*	*Upper Level*	*R^2*	*Adjusted R^2*	*F-test*	*p-value*
							0.272	0.260	22.506	0.0001
EQ-5D score	2.019	0.134	0.495	0.001	1.757	2.282				
Age family member	-0.044	0.030	-0.073	0.144	-0.102	0.015				
Survivor's weeks since first had COVID-19	-0.064	0.043	-0.048	0.144	-0.149	0.022				
Family member gender	-1.357	0.587	-0.080	0.021	-2.510	-0.204				
Have you also had COVID-19?	1.138	0.524	0.071	0.030	0.109	2.167				
Relationship										
parent	-1.061	1.204	-0.033	0.379	-3.426	1.303				
sons and daughters	-3.243	1.108	-0.123	0.004	-5.419	-1.067				
brothers and sisters	-4.079	1.476	-0.090	0.006	-6.977	-1.180				
other	-2.728	1.827	-0.048	0.136	-6.314	0.859				
Survivor age	-0.040	0.032	-0.059	0.201	-0.103	0.022				
Survivor existing health condition	0.658	0.574	0.038	0.252	-0.468	1.785				
Survivor hospital stay for COVID-19	0.547	0.660	0.027	0.408	-0.749	1.842				

*Multiple regression; *B=the slope of the line between the predictor variable and the dependent variable – the larger the number, the more spread out the points are from the regression line; F-test=degree of the linear regression model fitting the data;* R^2 *= how well the model fits the data; Males=1 and females =0; females are the reference group.*

DISCUSSION

This study fills an important knowledge gap in measuring the impact of COVID-19 on the HRQoL of both the survivors and, importantly, their partners and family members. Health-related quality of life is defined as a person's perception of his/her physical, mental, social and overall well-being (8, 9). Therefore, its assessment embraces a wider view of the impact of COVID- 19.

This study has revealed that the pandemic has a major impact on lives of those who have survived the infection. The survey depended on the patient's self-report of the diagnosis of COVID-19 infection and did not specifically ask whether patients had had a COVID-19 positive test. However, further authentication of the diagnosis is given by both the patient and their relative having answered the survey. Pain and discomfort were the most frequently reported problem by COVID-19 survivors, followed by impact on their usual activities, anxiety and depression, affecting females to a greater extent. As the majority of COVID-19 survivors were in paid employment, being physically unwell might have impacted their usual activities or return to work. According to a review on return to work after critical illness (10), globally, a third of previously employed survivors after intensive care stays remained out of work after five years.

In the survey, COVID-19 survivors were asked whether they were 'already suffering from some existing chronic health condition (such as diabetes, heart disease, lung disease)' prior to the infection with COVID-19. Survivors with existing health conditions did not differ significantly from those without such conditions except for mobility and usual activities however, having an existing health condition was not a significant predictor of impact on the family member/partner's QoL. The survivor's QoL was impacted greatly irrespective of having a existing health condition as it was not clear predictor of EQ-5D scores in regression analysis. Hospitalised survivors reported greater impact on mobility, self-care and usual activities compared to those who had not been hospitalised. This survey did not ask respondents whether those hospitalised were admitted to ICU. So we are not able to draw any conclusion concerning the relationship of admission to ICU to later QoL.

The study also revealed a major impact on QoL of the survivors' partners and family members with partners being most impacted. Currently Minimal Clinically Important Difference (MCID) for

FROM-16 has not been published; however, MCID values for such questionnaires usually are approximately 10-20% of the total score range, and so we would expect the FROM-16 MCID to be approximately 3 to 6. If this is the case, the statistically significant differences reported would also be clinically significant. Nearly half of participating partners and family members also reported having had COVID-19. Although there were no significant differences between the family members with COVID-19 and those without across 10 of the 16 QoL items of FROM-16, eating habits, family activities, holiday, sleep, sex-life and work or study were impacted significantly more in those who had had COVID-19. Overall FROM-16 scores were higher for partners and family members with COVID-19 after adjusting for age, gender, relationship to survivor and the overall survivors' EQ-5D scores, thus indicating poorer QoL for family members with COVID-19 than for those without.

Most partners and family members reported being worried and frustrated, many reported sadness, inability to talk to someone and difficulty in caring for their loved ones. This is not surprising in a situation with constant media coverage with emphasis on high daily death rates, the fear of infecting loved ones, stigma due to community or family members blaming survivors for the spread of the illness, isolation of loved ones, inability of a family member to provide support, and prolonged recovery time (11). Such stressors have been implicated in the poor psychological and emotional health of survivors and their family members (11-14).

Family members reported an impact on sexual life as a result of their relative's COVID-19 and this impact was higher in males and in family members who has also contracted COVID-19. Two-thirds of family members were either spouses or partners, who could have experienced these difficulties because of the contagious nature of COVID-19 and because of post survival symptoms. Moreover, physical illness in partners has a significant impact on marital relationships, contributing to marital dissatisfaction and likelihood of later divorce (15). Over half of partners and family members reported impact on holidays and nearly half reported an increase in expenses due to their relative's COVID-19.

One of the key findings of this study is the evidence that in survivors in whom the COVID-19 onset was more than 12 weeks ago, there was still a major persisting impact on QoL across all domains in both survivors and family members. This provides further evidence of the severe impact of post-acute COVID-19 ("Long COVID") and "Chronic COVID" (16). According to NICE, the term 'long COVID' " is commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more)" (17). The term 'Persisting' refers to the continuity of the impact of COVID-19 on survivor's health since the onset of COVID-19 infection.

Interestingly, of the patients who participated, most (76.6%) were women, as found in other surveys(18); however, there was a higher proportion of men among participating family members (66.5%). This may be because the majority of COVID-19 social media support groups have been initiated by women (patients), and the most convenient family person to ask to participate might be their partners (mostly male).

Comparison with other studies

Chinese survivors of COVID-19 reported lower HRQoL with significant impact on their physical and psychological health, one month after recovery (19). Our study has shown a major impact not only on the HRQoL of survivors of COVID-19 but also on their partners and family members. This is consistent with the findings of Golics et al. (2, 20) that multiple elements of family members' lives can be affected by a relative's illness including emotional, financial, family relationships, education and work, leisure time, and social activities.

Our study has shown that most (87%) survivors had COVID-19 for more than 4 weeks, and 64% more than 12 weeks indicating that survivors continued to remain unwell for long periods of time, due to post-viral symptoms or 'long COVID'. This is in contrast to a UK COVID-19 symptom study (21), where only 10% of COVID-19 positive survivors remained unwell at three weeks, and a small proportion for more than three months. An online survey of British doctors in August 2020 revealed that many were being treated for long term COVID-19 symptoms such as chronic fatigue, muscle weakness, loss of sense of smell, and concentration difficulties (22)

In our study 69% COVID-19 survivors reported feelings of anxiety and depression, much higher than the 43.1% reported by Ma Y-F et al. (9) in clinically stable patients with COVID-19. Previous studies of Severe Acute Respiratory Syndrome (SARS) revealed the persistence of depression in patients up to 30 months after discharge from hospital (23, 24).

Several studies have shown the impact of COVID-19 on sleep patterns of survivors, with an increase in prevalence of insomnia (25-27). We do not know whether the sleep patterns of survivors in our study were also impacted, since EQ-5D does not include such an item. However, in our study 69 % of partners and family members experienced problems with sleep, and 32% reported that their sleep was impacted “a lot”.

The total mean domain scores for FROM-16 in this study were 6.12 (Emotional) and 8.88 (Personal and Social Life) which are higher than the mean domain scores reported by Golics et al. (5) (Emotional=5.6; Personal and Social Life=6.7) on the impact of patients’ chronic disease on family members across 26 medical specialties. Another study (4) reported the mean domain scores of family members of patients with cancer as Emotional=4.7 and Personal and Social Life=7.1. In a FROM-16 study on family members of patients with urinary stone disease, family members were not impacted much by their relative’s disease, however they reported a slightly greater degree of change in the ‘emotional’ domain compared with the ‘personal and social life’ domain (28). This indicates that family members of COVID-19 survivors suffered more than family members of patients with other severe chronic diseases.

Strengths and Limitations.

This study to our knowledge is the first global study to explore the impact of COVID-19 on both survivors and also their family members/partner. Other strengths include the large sample size, heterogenous population and use of validated tools to assess QoL impact. The study has demonstrated use of the FROM-16 questionnaire for studying the effects of a pandemic on family members of an infected person.

This study has several limitations. Firstly, it suffers from considerable selection bias as only those COVID-19 survivors and family members who could access the internet and were active on social media completed the online questionnaires, limiting generalisability of the study findings. It is also possible that people who experienced persisting symptoms may have been more likely to have participated in the study. This survey was conducted internationally in the English language. Although FROM-16 is available to researchers in several languages, our full survey documents and the participant information sheet were only available to the participants in the English language, and in the survey FROM-16 was also only provided in English. Participants could only take part if they could understand all of the documentation. The ability of some respondents to read and understand English may have been limited, but we are not able to assess this. However, during the development of, in particular, FROM-16, the following issues were considered as part of its conceptualisation and development in order to improve its universality and translatability:1) applying readability to the level of understanding of a 12 year old; 2) formatting of the items into short and complete sentences of about six words to enhance clarity of meaning; 3) ensuring ease of understanding to allow future cross-cultural adaptation, facilitating universality and translatability. Although we did not develop the EQ-5D, that questionnaire was also designed to be as universally understandable as possible. Concerning the wider survey questions, we took several steps in the development of the survey to ensure maximum comprehensibility:1) We ensured that the readability was acceptable to a 12-year-old standard; 2) We carried out an international pilot including participants for whom English was not their first language and made adjustments accordingly; 3) The survey was reviewed by our patient study research partners.

Secondly, the study, being cross-sectional, cannot establish causal relationships among the study variables. Because of the nature of the study, we could not collect any baseline measurements (pre-COVID-19 measurements). We are, therefore, not able to differentiate between the effect of COVID-19 infection or of a pre-existing physical or mental state. However, only 30.9% of respondents had any existing health condition, and therefore this limitation only refers to this small proportion of respondents. In addition, as all the covariates in the study were self-reported, data on hospitalisation and medical problems could be inaccurate and is a potential limitation(29). This study does not have a control group but in healthy volunteers in the UK, mean EQ-5D scores were EQ-VAS = 82.75, Mobility = 0.18, Self-Care = 0.04, Usual Activity = 0.16, Pain/Discomfort = 0.33, Anxiety / Depression = 0.20 (30). In contrast, COVID-19 survivors (47.1 % of survey respondents were from the UK) in our study had mean scores of EQ-VAS = 55.83, Mobility = 1.59, Self-Care = 1.23, Usual Activity = 2.06, Pain / Discomfort = 1.93, Anxiety / Depression = 1.84. This suggests that overall HRQoL was highly impaired in the COVID-19 survivors across all domains. Furthermore, the study was carried out between June and August 2020 when the severity of the pandemic varied among different countries. Therefore, the study results may have been influenced by the specific local and governmental measures in place at the time. It is likely that participants will have been living under different government restrictions, thereby possibly influencing responses to the questionnaires. However, because of the complexity of the international situation, we are not able to account for this. Although formal cultural adaptation of the survey questionnaire was not carried out, we endeavoured to ensure maximum understandability and acceptability. It should be noted that the questions asked are mostly universal in nature and do not refer to culturally specific practices such as semantic differences. However, despite these limitations, the study has provided a rapid overview of survivors' and their family members' HRQoL and revealed evidence of the substantial persisting effect on QoL of survivors and a major secondary impact on the lives of partners and family members. This information can be used to inform policymakers about the health needs of these individuals and may encourage the development of tailor-made support services.

Implications for clinicians and policymakers

Our results have shown how the impact of COVID-19 on one family member can have a domino effect on other family members, especially those close to them such as partner, parents and children. It is important to understand the needs of these impacted family members and survivors to ensure the overall wellbeing of the family unit. Based on the findings of this study, policymakers should consider developing and commissioning the following support services for survivors and family members:

Post COVID-19 clinics: Survivors reported pain and discomfort even after 12 weeks of COVID-19, indicating that tailored services to deal with such symptoms are important to help survivors suffering with long term sequelae. Survivors with post-COVID-19 complications should be heard and treated. Although such clinics have been started in a few countries, there is a considerable need for such initiatives globally.

Needs-based mental health counselling: Most family members and survivors reported being depressed and worried. It is imperative to further develop care services to ensure the mental wellbeing of survivors and their family members.

Physical activity and rehabilitation services: Most survivors have reported pain and discomfort and an inability to do their normal activities. Rehabilitation clinics could provide emotional and physical support to physically and emotionally drained survivors and their family members to enable their return to normal routines.

Social support services: Patients with COVID-19 are from diverse backgrounds and therefore will benefit from culturally and socially appropriate support. Financial assistance is particularly important for those who do not have health insurance to cover COVID-19 expenses.

Patient support groups/local support groups for COVID-19 survivors and family members: Local support groups could be used in primary care settings and can help by significantly combating isolation and the disability the study has identified that occurs in COVID-19 survivors and their family members/partners. This could in turn have health economic benefits by possibly reducing long-term utilisation of mental health services. Similar approaches have been successful, for example in supporting people with myalgic encephalitis.

Future research and recommendations

Although this study provided an overview of the impact of COVID-19 on survivors' partners and family members, it was not designed to identify causal relationship. Future longitudinal studies are needed to understand the long-term impact of COVID-19. As COVID-19 is still a major challenge, with people experiencing 'long COVID', there is a need for further research including long term studies to better understand 'long COVID' and its impacts on survivors and family members. However, the way the participants were recruited for the current study does not allow us to have access to follow-up data from this cohort. We were unable to measure the impact of COVID-19 on sleep and sex-life of survivors, future studies should measure such impacts.

CONCLUSION

Survivors of COVID-19 report a major persisting impact on their QoL with many feeling unwell beyond 12 weeks. This indicates a demand for a holistic support system that is sensitive to their needs. Moreover, the QoL of partners and family members is also severely impacted, demonstrating the importance of investigating disease impact on family QoL. The establishment of services to provide support to family members of survivors and patients in general is therefore a key consideration in the future management of COVID-19. Although the recruitment method used inevitably leads to some degree of selection bias which in turn may dilute the generalisability of the study findings, the central conclusions of this study, that COVID-19 has a profound and long-lasting impact on survivors and their family members continue to remain valid.

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Competing interests: All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no support from any organisation for the submitted work; RS and SJN declared no competing interest, AYF and SS are joint copyright owners of Family Reported Outcome Measure (FROM-16). JRI reports personal fees from UCB Pharma, personal fees from Novartis, personal fees from Boehringer Ingelheim, personal fees from Kymera Therapeutics, personal fees from Viela Bio, personal fees from UpToDate, personal fees from Editor of British Journal of Dermatology, outside the submitted work; in addition, JRI is co-copyright holder of the Hidradenitis Suppurativa Quality of Life (HiSQOL) score. FMA reports grants and personal fees from Janssen, personal fees from Abbvie, personal fees from Lilly Pharmaceuticals, personal fees from L'Oreal, personal fees from LEO Pharmaceuticals, personal fees from UCB, outside the submitted work.

Author contributions: RS primarily carried out the study. wrote first drafts and revised all documentation. SS and AYF equally contributed to the design and supervision of the study and revised all study documentation and the manuscript. FMA, JRI and SJN provided advice during the study and helped revise study documentation. FMA, JRI and SJN reviewed the manuscript. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

Public and Patient Involvement (PPI): Twenty members of the public, including some work colleagues, participated in the pilot study. Some had experience of having COVID-19 patient in their family. The study sociodemographic questions were extensively modified following the outcome of the pilot study. The ‘patients and family member group’ consisting of two patients and one family member, were involved as study research partners. This group was involved in reviewing the study protocol, other related documents and the manuscript.

Ethical approval: Ethics approval was granted by the Cardiff University School of Medicine Research Ethics Committee (SMREC 20/60).

Data sharing: This paper does not report a trial. If requested, we are happy to share our data.

Transparency statement: The lead author RS affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Dissemination to participants and related patient and public communities: The summary of the results will also be disseminated by social media using the same methods as used for recruiting participants and made accessible to public and patients through the Cardiff University FROM-16 website page

Figure legends

Figure 1 COVID-19 survivor response to EQ-5D-3L (n=735)

Figure 2 Partner and family member response to FROM-16 items (n=735)

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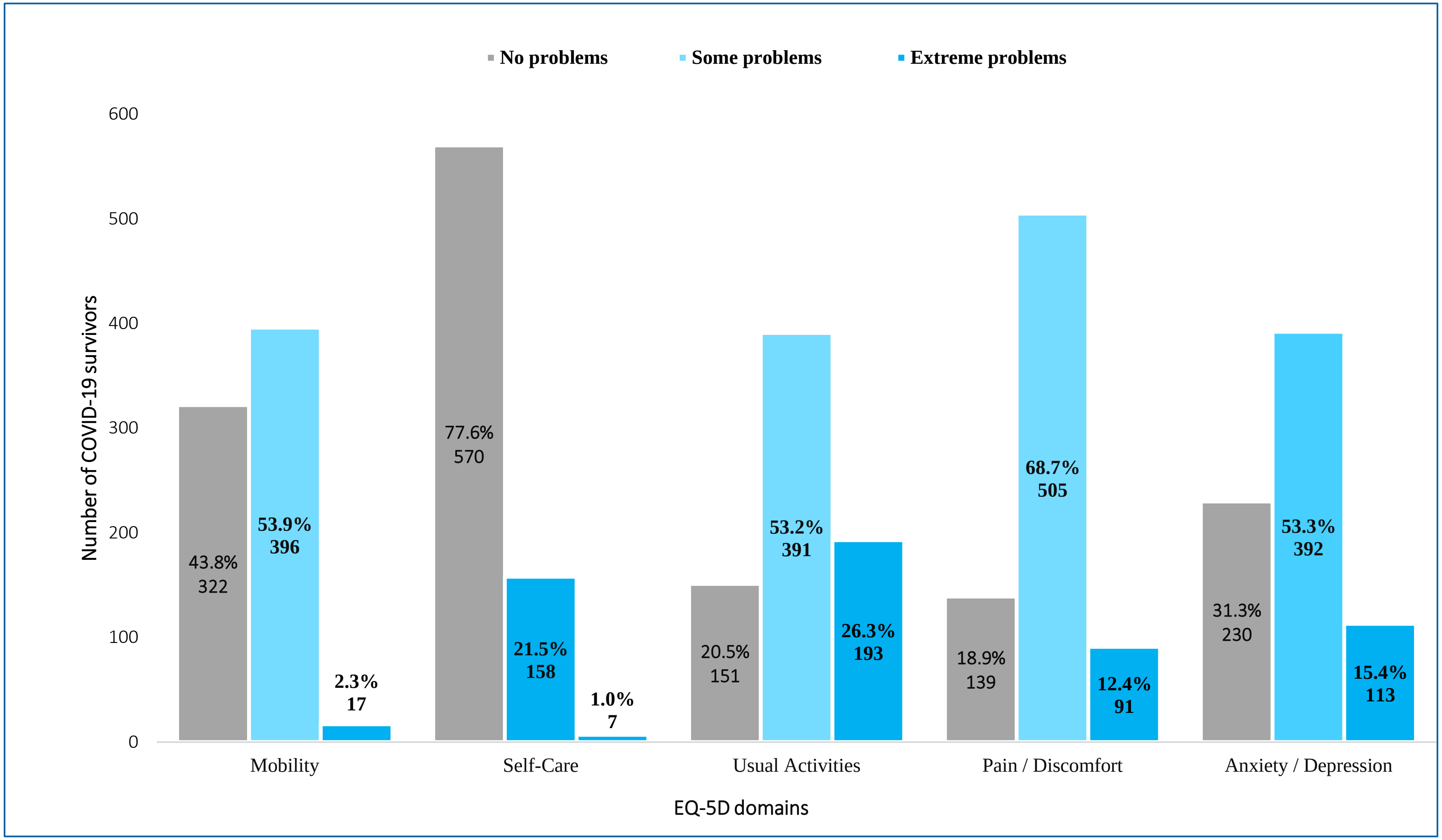
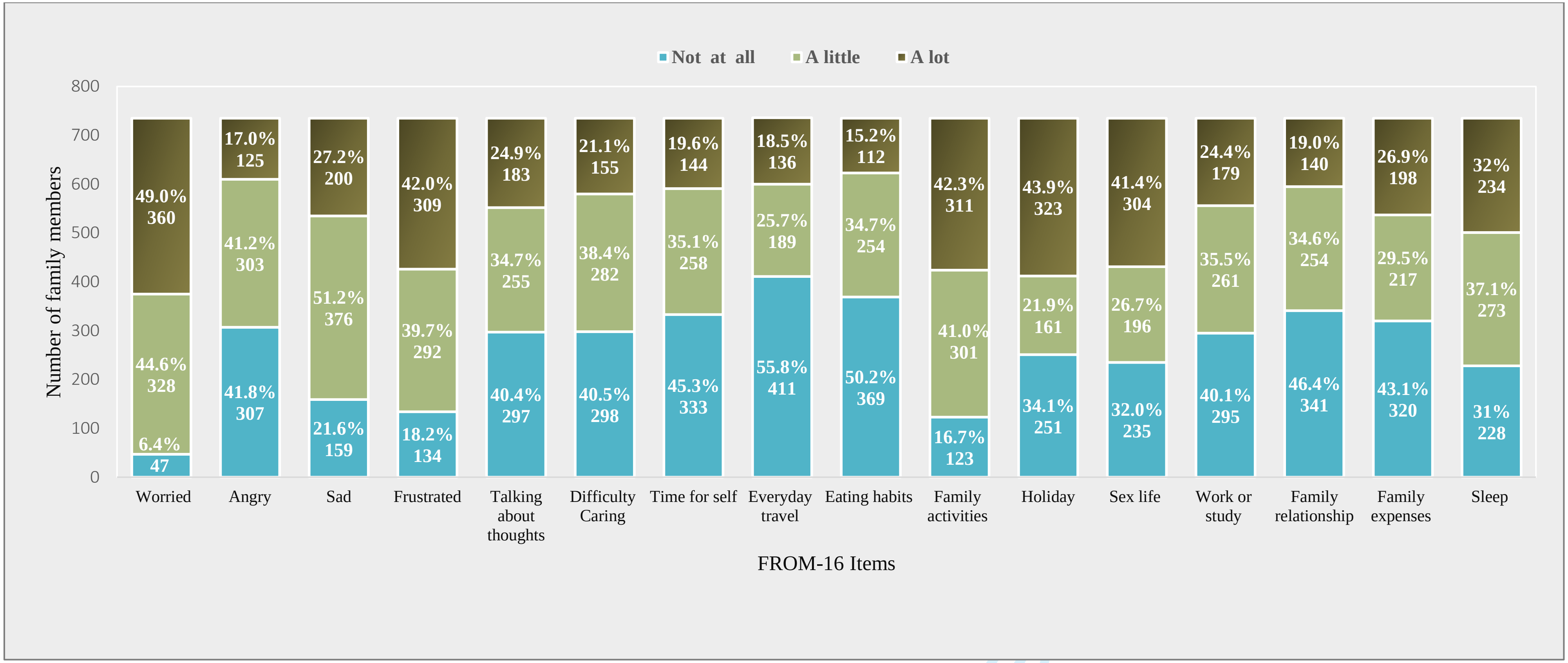
Figure1 COVID-19 survivor response to EQ-5D-3L (n=735)




Not at all
A little
A lot
Number of family members
800
700
600
500
400
300
200
100
0
FROM-16 Items
Worried
49.0% 360
44.6% 328
6.4% 47
Angry
17.0% 125
41.2% 303
41.8% 307
Sad
27.2% 200
51.2% 376
21.6% 159
Frustrated
42.0% 309
39.7% 292
18.2% 134
Talking about thoughts
24.9% 183
34.7% 255
40.4% 297
Difficulty Caring
21.1% 155
38.4% 282
40.5% 298
Time for self
19.6% 144
35.1% 258
45.3% 333
Everyday travel
18.5% 136
25.7% 189
55.8% 411
Eating habits
15.2% 112
34.7% 254
50.2% 369
Family activities
42.3% 311
41.0% 301
16.7% 123
Holiday
43.9% 323
21.9% 161
34.1% 251
Sex life
41.4% 304
26.7% 196
32.0% 235
Work or study
24.4% 179
35.5% 261
40.1% 295
Family relationship
19.0% 140
34.6% 254
46.4% 341
Family expenses
26.9% 198
29.5% 217
43.1% 320
Sleep
32% 234
37.1% 273
31% 228

Section/Topic	**Item #**	**Recommendation**	**Page No**	**Relevant text from the manuscript**
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	2	Abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2	Abstract page 1
Introduction				
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3	Introduction- paragraph 1, 2
Objectives	3	State specific objectives, including any prespecified hypotheses	4	Introduction- paragraph 3
Methods				
Study design	4	Present key elements of study design early in the paper	4, 5	Methods
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4-5	Methods-setting/ participants / procedure
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5	Method-procedure
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6	Methods -outcome /exposure/Covariates/missing data
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6	Methods-Measurements tools
Bias	9	Describe any efforts to address potential sources of bias	*7, 14-15*	Methods and Regression
Study size	10	Explain how the study size was arrived at		Study Size = Exploratory
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	7	Statistical analysis
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	7	
		(*b*) Describe any methods used to examine subgroups and interactions	7-17	Statistical analysis and Tables 1-7
		(*c*) Explain how missing data were addressed	7	There were no missing data
		(*d*) If applicable, describe analytical methods taking account of sampling strategy		Exploratory
		(*e*) Describe any sensitivity analyses		Not applicable

Results				
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7	Results section
		(b) Give reasons for non-participation at each stage		Not applicable
		(c) Consider use of a flow diagram		Not applicable
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7-8	Table 1 descriptive analysis
		(b) Indicate number of participants with missing data for each variable of interest		NA (no missing data)
Outcome data	15*	Report numbers of outcome events or summary measures	7	Results and Tables/Figures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included	7-17	Results section-Table 3, 4 and 5. Multiple regression Tables 6 and 7
		(*b*) Report category boundaries when continuous variables were categorised		Not Applicable
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period		Not Applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	10-13	Results – Sub group analysis-male /female; hospitalise for COVID-19/not hospitalised ; Pre-existing health condition / No pre-existing health condition; partner and Family member 's with COVID / Partner and family not having COVID Tables 3 and 4
Discussion				
Key results	18	Summarise key results with reference to study objectives	18-19	16-17
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	20	Strengths and Limitation section
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	20-21	Strengths and limitation / comparison with other studies

Generalisability	21	Discuss the generalisability (external validity) of the study results	20	Strengths and limitations section
Other information				
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based.	24	Funding section

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

BMJ Open

Measuring the impact of COVID-19 on the quality of life of the survivors, partners and family members: A cross-sectional international online survey

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Measuring the impact of COVID-19 on the quality of life of the survivors, partners and family members: A cross-sectional international online survey

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ABSTRACT

Objective:
This study aimed to measure the impact of COVID-19 on the quality of life (QoL) of survivors and their partners and family members.

Design and Setting:
A prospective cross-sectional global online survey using social media.

Participants:
COVID-19 patients and partners or family members (age ≥18 years).

Intervention:
Online survey from June to August 2020.

Main outcome measure:
The EQ-5D-3L to measure the QoL of survivors of COVID-19, and the Family Reported Outcome Measure (FROM-16) to assess the impact on their partner/family member's QoL.

Results:
The survey was completed by 735 COVID-19 survivors (mean age=48 years; females=563) at a mean of 12.8 weeks after diagnosis and by 571 partners and 164 family members (n=735; mean age=47 years; females=246) from Europe (50.6%), North America (38.5%) and rest of the world (10.9%). The EQ-5D mean score for COVID-19 survivors was 8.65 (SD=1.9, median=9; range=6-14). 81.1% (596/735) reported pain and discomfort, 79.5% (584/735) problems with usual activities, 68.7% (505/735) anxiety and depression and 56.2% (413/735) problems with mobility. Hospitalised survivors(20 %, n=148) and survivors with existing health conditions (30%, n=227) reported significantly more problems with mobility and usual activities ($p<0.05$), with hospitalised also experiencing more impact on self-care ($p\leq0.001$).

Among 735 partners and family members, the mean FROM-16 score (maximum score = highest impact =32) was 15 (median=15, range=0-32). 93.6% (688/735) reported being worried, 81.7% (601/735) frustrated, 78.4% (676/735) sad, 83.3 % (612/735) reported impact on their family activities, 68.9% (507/735) on sleep and 68.1% (500/735) on their sex life.

Conclusion:
COVID-19 survivors reported a major persisting impact on their physical and psychosocial health. The lives of their partners and other family members were also severely affected. There is a need for a holistic support system sensitive to the needs of COVID-19 survivors and their family members who experience a major "secondary burden".

Keywords
COVID-19; Long COVID, family impact; partner impact; patient impact; EQ-5D; quality of life; FROM-16; Family- Reported Outcome Measure.

Strengths and Limitations of this study

- This study provides evidence of the impact on quality of life (QoL) of ‘Long COVID’ in survivors of COVID-19.
- This study fills an important knowledge gap in measuring the impact of survivors’ COVID-19 on the QoL of partners and other family members.
- Large sample size, heterogenous population and use of validated tools to assess QoL impact
- The study was open to COVID survivors and their family members internationally, but only those active on social media who could read and understand English completed the survey.
- Causal relationships cannot be established among the study variables as the study was cross-sectional.

INTRODUCTION

The COVID-19 pandemic is causing profound changes across the world, but there is little information on its physical and psychosocial impact on survivors and their families. Despite the need (1) for information on the lived experience of infected individuals and their family members, there are only sparse data available.

It is important to ascertain COVID-19’s immediate and persisting (Long COVID) impact on those affected and on their families in order to aid healthcare workers and government agencies to better support them. The understanding of how a person’s health condition impacts the quality of life (QoL) of other family members has increased over the last decade (2).

The aim of this study was to assess the impact of COVID-19 on survivors and their family members based on their lived experience of COVID-19 using validated QoL instruments administered using online social media platforms.

METHODS

Settings and participants

This was a prospective cross-sectional global online survey, using an anonymous online questionnaire. The survey was carried out using https://www.onlinesurveys.ac.uk/ on a Jisc platform (3). The survey was distributed through social media platforms including Facebook, Twitter, LinkedIn, WhatsApp and Reddit.

Procedure

Ethics approval was granted by the Cardiff University School of Medicine Research Ethics Committee (SMREC 20/60). Study participants were provided with information about the study via a link in the survey to a "Participant Information Sheet" where they were informed that participation was voluntary and their data would remain anonymous. Those who decided to take part gave informed consent at the beginning of the survey. Data collection took place from 30th May to 30th August 2020.

The study was only open to individuals who were diagnosed with COVID-19 and their family member or partner, adults aged 18 years or above who could read and understand English, and who were able to give written consent and complete the questionnaire using an electronic device. Participants were excluded if they had not had COVID-19 or if they were less than 18 years of age.

Survey development

The survey included two QoL questionnaires: EuroQol group 5 Dimensions 3 level (EQ-5D-3L) and Family Reported Outcome Measure (FROM-16). There were additional socio-demographic questions such as responder’s age, gender and country of residence (Table 1). A pre-test draft survey was piloted during May 2020 in 20 individuals without COVID-19 across several countries including the UK, India, and the UAE. Views were also sought from the study research partners, a patient and two family members. The survey questions were revised based on the collective feedback.

Patient and public involvement

Two patients and one family member were involved as integral study research partners, one of whom (SJN) is a co-author. They were involved in reviewing the study protocol, drafting the survey, reviewing the manuscript and providing suggestions from the patient and family perspective.

Survey structure

The survey had two sections. Section one was completed by the COVID-19 survivor. Each survivor provided basic demographic details and provided EQ-5D-3L responses. Section two was completed by the partner or a family member of the survivor who provided basic demographic details and completed FROM-16. The survey did not specify whether this should be someone the patient lives with or whether it could be any close relation; however, the family member of the COVID-19 survivor was asked to specify their relationship to the patient.

Measurement tools

The EQ-5D-3 L is a self-reported generic health-related QoL (HRQoL) instrument that specifically addresses health status (4). It consists of five questions on mobility, self-care, usual activities, pain and discomfort, and anxiety and depression with 3-point response categories (1= no problems, 2= some problems and 3= serious or extreme problems). The EQ-VAS component of EQ-5D-3L asks respondents to rate their overall health status from 0 (worst imaginable health) to 100 (best imaginable health). In this study, for simplicity throughout this manuscript, we refer to EQ-5D-3L as 'EQ-5D'.

The FROM-16 measures the impact of a patient's disease on the QoL of a family member or partner of a patient (5). The FROM-16 comprises 16 items with 3-point response options for each: not at all (scoring 0), a little (1) and a lot (2), with a total score range of 0 - 32. The higher the score, the greater the negative impact on the family member's QoL. The 16 items are divided into two domains: Emotional (six items, maximum score12) and Personal and Social Life (ten items, maximum score 20). The FROM-16 has proven psychometric properties, a rapid completion time of two minutes (5) and translations are available in several languages (6). A generic measure, the FROM-16 has been validated across all areas of medicine (5-7) and is therefore suitable for measuring the impact of

COVID-19 on the partner and family members of those affected. As it is a generic measure, data generated can be compared with data from other medical conditions.

Outcome: The impact of COVID-19 on the quality of life of survivors and their partners and family members.

Exposure: COVID-19 infection of the participant or of the family member.

Covariates: The covariates included hospital stay due to COVID-19 infection, existing health condition of survivors, number of weeks since COVID-19 diagnosis, partners and family members diagnosed with COVID-19, family members' relationship to survivors, country of residence, age and sex of family members and survivors. All the covariates, including hospitalisation, existing conditions and number of weeks since COVID-19 diagnosis were based on self-report.

Missing data: There were no missing data, but two responses were ambiguous for one of the variables (EQ-VAS) and were excluded from the analysis.

Statistical analysis

Descriptive statistics (i.e. mean, standard deviation, median, inter-quartile range) were performed for all variables. The Shapiro–Wilk test was used to examine normal distribution of continuous variables. The required assumptions for normal distribution were not met. Consequently, data analysis employed non-parametric statistical method. Both the EQ-5D-3L and the FROM-16 scores were treated in the analysis as dependent variables. The EQ-VAS component of EQ-5D was examined separately as a dependent variable. To determine differences between groups defined by each outcome, chi-square tests (when appropriate, Fisher's exact tests) and Mann-Whitney U tests were computed. These bivariate comparisons were based on COVID-19 survivor's characteristics (gender, existing health condition, and hospitalisation) and family member characteristics (gender and whether diagnosed with COVID-19). Spearman's rank correlation coefficient and multiple regression analysis were conducted to understand the effect of independent variables (i.e. predictors: survivor age, existing health condition, hospital stay for COVID-19, number of weeks since COVID-19 diagnosis, survivor gender) on the EQ-5D outcomes. Similarly, these analyses were conducted to understand the effect of independent variables (EQ-5D score, age family member, number of weeks since COVID-19 diagnosis, family member gender, whether family member also had COVID-19, relationship to survivor, survivor age, survivor existing health condition, survivor hospital stay for COVID-19) on the FROM-16 outcomes. Statistical Product and Service Solutions SPSS® (version 25) was used and the probability of type I error was set at $p < 0.05$.

RESULTS

Sociodemographic characteristics of the study participants

A total of 1,254 respondents consented to participate in the survey: 765 completed both sections. Thirty responses were excluded as the respondents were below the age of 18 years. The final analysis included 735 COVID-19 survivors and their family members/partner from Europe (50.6%), North America (38.5%) and the rest of the world (10.9%) (Table 1).

Table 1 Sociodemographic characteristics of the study participants

Variables	Categories	N (%) or N(SD)
COVID-19 Survivors (n=735)		
Gender	Male	172 (23.4%)
	Female	563 (76.6%)
Age (years)	Mean (SD)	47.77 (11.656)
	Median	48.00
	Range	19-85
	Range (IQR)	19-85 (16)
Number of weeks since COVID-19 diagnosis	Mean (SD)	12.76 (6.104)
	Median	13.00
	Range	1-36
	Range (IQR)	1-36 (8)
	≥4 weeks	98 (13.3%)
	5-11 weeks	170 (23.1%)
	≥12 weeks	467 (63.5%)
Occupation	Unemployed	19 (2.6%)
	In paid work	538 (73.2%)
	In education or training	26 (3.5%)
	In unpaid work	7 (1%)
	Work in the home/manage the family	60 (8.2%)

	Retired	66 (9%)
	Rather not say	19 (2.6%)
Existing health conditions	No	508 (69.1%)
	Yes	227 (30.9%)
Hospitalised for COVID-19	No	587 (79.9%)
	Yes	148 (20.1%)
Regions	Europe	372 (50.6%)
	North America	283 (38.5%)
	Rest of the World	80 (10.9%)
Family members (N=735)		
Gender	Male	489 (66.5%)
	Female	246 (33.5%)
Age (years)	Mean (SD)	47.43 (13.582)
	Median	48.00
	Range	18-87
Occupation	Unemployed	42 (5.7%)
	In paid work	530 (72.1%)
	In education or training	29 (3.9%)
	In unpaid work	18 (2.4%)
	Retired	95 (12.9%)
	Rather not say	21 (2.9%)
Relationship to the person affected with COVID-19	Spouse/Partner	571 (77.7%)
	Parents	48 (6.5%)
	Son/Daughter	77 (10.5%)
	Brother/Sister	24 (3.3%)
	Other	15 (2%)
Diagnosed with COVID-19	No	380 (51.7%)
	Yes	355 (48.3%)

Of the 735 COVID-19 survivors, 76.6% were females (mean and median age=48 years) and 73.3% were in paid employment. The mean time since COVID-19 symptoms started was 12.8 weeks (median=13 weeks). In 86.6% (n=637) > 4 weeks had elapsed since COVID-19 symptoms started and in 63.5% (n=467) >12 weeks had elapsed. Of the family members (mean age=48 years, median=47 years), 66.5 % were male and 72.1% were in paid employment. Most of the family members were partners (77.7%), followed by sons and daughters (10.5%) and parents (6.5%). In addition, 48.3 % of the family members had also contracted COVID-19 (Table 1).

Quality of life impact of COVID-19 on survivors

The EQ-5D mean score was 1.73 (SD=0.39) with the 'usual activities' item scoring the highest (mean=2.06, max 3) followed by pain/discomfort (1.93) and anxiety/depression (1.84). The mean score of the visual analogue part of EQ-5D was 56 (SD=22.94) (Table 2).

Table 2 Mean scores of EQ-5D and FROM-16 (n=735)

Scale	Mean (SD)	Median (interquartile range)	Range
EQ-5D-3L domains			
Overall	8.65 (1.97)	9 (3)	6-14
Mobility	1.59 (0.54)	2 (1)	1-3
Self-Care	1.23 (0.45)	1 (0)	1-3
Usual Activities	**2.06** (0.68)	2 (1)	1-3
Pain / Discomfort	**1.93** (0.56)	2 (0)	1-3
Anxiety / Depression	**1.84** (0.67)	2 (1)	1-3
EQ-VAS n(733)	55.83 (22.94)	60(35)	3-100
FROM-16			
Overall	15.00 (8.05)	15 (13)	0-32
Emotional Domain	6.12 (3.23)	6.0 (5)	0-12
Worried	**1.43** (0.61)	1 (1)	0-3
Angry	0.75 (0.73)	1(1)	0-3
Sad	**1.05** (0.70)	1 (1)	0-3
Frustrated	**1.24** (0.74)	1 (1)	0-3
Talking about thoughts	0.84 (0.79)	1 (1)	0-3
Difficulty caring	0.81 (0.76)	1 (1)	0-3
Personal and Social Domain	8.88 (5.51)	9.0 (9)	0-20
Time for self	0.74 (0.76)	1 (1)	0-3
Everyday travel	0.63 (0.78)	0 (1)	0-3
Eating habits	0.65 (0.73)	0 (1)	0-3
Family activities	**1.26** (0.73)	1 (1)	0-3
Holiday	**1.10** (0.88)	1 (2)	0-3
Sex life	**1.09** (0.85)	1 (2)	0-3
Work or study	0.84 (0.79)	1 (1)	0-3
Family Relationship	0.73 (0.76)	1 (1)	0-3
Family expenses	0.83 (0.82)	1 (2)	0-3
Sleep	**1.01** (0.79)	1(2)	0-3

Of the five dimensions of EQ-5D, 'pain and discomfort' was the impact most frequently reported (81.1%; 68.7 % some problems and 12.4% extreme problems), followed by usual activities (79.5%; 53.2% and 26.3%) and anxiety and depression (68.7%; 53.3% and 15.4%) (Figure 1). There was a significant gender difference for ‘mobility’ and for ‘pain and discomfort’ ($p \leq 0.05$) with females being more impacted than males (Table 3).

Although existing health conditions were self-reported and severity was not stated, survivors with existing health conditions did not appear to differ from those without such conditions except for mobility $p \leq 0.05$) (Table 3). Having an existing health condition was not a clear predictor of impact on the family member/partner’s QoL.. There was a significant difference between the survivors who had been hospitalised for COVID-19 (20%) and those who had not, with the hospitalised survivors being more severely affected across mobility, self-care ($p \leq 0.001$) and usual activities ($p \leq 0.02$) (Table 3).

There were significant differences in EQ-5D mean scores between survivors with respect to number of weeks since COVID-19 diagnosis ($p<0.001$). Mean EQ-5D scores of survivors having COVID-19 symptoms for up to 4 weeks was 8.03 (SD=1.97), 5-11 weeks was 8.3 (SD=2.13) and 12 weeks and above was 8.9 (SD=1.86).

, Table 3 Comparisons [†] of EQ-5D scores for gender, existing health condition and hospitalisation

EQ-5D domain	Gender Mean score		p-value**	Existing health condition Mean score		p-value**	Hospitalised for COVID-19 Mean score		p-value**
	Male (n=172)	Female (n=563)		Yes (n=227)	No (n=508)		Yes (n=148)	No (n=587)	
Overall	8.33	8.74	**0.036**	8.89	8.54	**0.012**	9.17	8.51	**0.001**
Mobility	1.51	1.61	**0.037**	1.67	1.55	**0.006**	1.75	1.54	**0.0001**
Self-Care	1.22	1.24	0.602	1.28	1.21	0.053	1.36	1.20	**0.0001**
Usual Activities	1.97	2.08	0.065	2.14	2.02	**0.034**	2.19	2.02	**0.009**
Pain / Discomfort	1.82	1.97	**0.002**	1.93	1.94	0.989	1.99	1.92	0.141
Anxiety / Depression	1.81	1.85	0.611	1.88	1.82	0.289	1.88	1.83	0.427

[†] Mann Whitney U test

**p values were calculated using mean rank scores but mean scores are presented here for ease of understanding.

Quality of life impact of COVID-19 on family members

The mean FROM-16 score was 15, reflecting the extent of the impact of the survivors' COVID-19 on the HRQoL of their family members (Table 2). The mean score of each of the 16 items is given in Table 2 with 'Feeling worried' scoring highest (1.46) followed by family activities, frustration, holiday, and sex life (1.26, 1.24, 1.10 and 1.09, respectively) (Table 2). Of the FROM-16 items, the feeling of being worried was most frequently reported (93.6%; 44.6% a little, 49% a lot), followed by family activities (83.3%; 41% , 42.3%), feeling of frustration (81.7%; 39.7% , 42%), feeling sad (78.4%; 51.2%, 27.2 %), sleep (68.9%; 37.1%, 31.8 %) and sex life (68.1%; 26.7%, 41.4%) (Figure 2).

There was a significant gender difference among family members, with females feeling more sad, experiencing more impact on everyday travel ($p\leq 0.01$) and on their sleep $p\leq0.05$). The impact on sex life was experienced significantly more by males than females ($p\leq 0.001$) (Table 4).

Table 4 Comparisons†of FROM-16 scores for gender and for whether diagnosed with COVID-19 (n=735)

FROM-16 Items	Gender Mean score Male (n=489)	 Female (n=246)	p-value**	Diagnosed with COVID-19 Mean score Yes (n=355)	 No (n=380)	p-value**
Overall	14.81	15.36	0.401	15.74	14.32	**0.017**
Worried	1.40	1.48	0.068	1.46	1.39	0.135
Angry	0.73	0.79	0.332	0.77	0.74	0.519
Sad	1.00	1.16	**0.004**	1.09	1.03	0.225
Frustrated	1.23	1.26	0.569	1.30	1.18	0.054
Talking about thoughts	0.83	0.87	0.651	0.89	0.80	0.132
Difficulty caring	0.79	0.85	0.324	0.81	0.80	0.847
Time for self	0.70	0.83	**0.036**	0.78	0.71	0.164
Everyday travel	0.58	0.72	**0.048**	0.64	0.62	0.874
Eating habits	0.64	0.67	0.565	0.72	0.59	**0.015**
Family activities	1.28	1.21	0.144	1.32	1.20	**0.041**
Holiday	1.10	1.10	0.992	1.17	1.03	**0.030**
Sex life	1.22	0.84	**0.000**	1.17	1.03	**0.035**
Work or study	0.83	0.87	0.485	0.92	0.77	**0.013**
Family relationships	0.69	0.79	0.109	0.75	0.70	0.281
Family expenses	0.81	0.87	0.367	0.84	0.83	0.759
Sleep	0.98	1.07	0.138	1.12	0.90	**0.000**

†Mann Whitney U test;
**p values were calculated using mean rank scores but mean scores are presented here for ease of understanding.

Those with a COVID-19 history experienced a greater impact on eating habits, work and study, family activities, holiday ($p \leq 0.05$), sex life and sleep ($p \leq 0.001$). There were no significant differences for the remaining 10 items of FROM-16 (Table 4).

There were significant differences in FROM-16 mean scores between family members of survivors with respect to onset of COVID-19 symptoms ($p<0.01$). Mean FROM-16 scores of family members of survivors having COVID-19 symptoms for up to 4 weeks was 16.11 (SD=7.35), 5-11 weeks was 13.31 (SD=7.77) and 12 weeks and above was 15.38 (SD=8.21).

Relationship between the quality of life of survivors and their family members

There were significant positive correlations between the EQ-5D score and the survivors' gender, hospital stay, existing health condition and number of weeks since COVID-19 diagnosis ($p <0.05$, $p < 0.001$) (Table 5).

There was a significant positive association between the family members' FROM-16 scores and the survivors' EQ-5D scores ($p <0 .001$) (Tables 5) and a significant negative association between FROM-16 scores and the family members' age, survivors' age and EQ-VAS scores ($p < 0.05$).

The EQ-VAS scores showed a significant inverse relationship with EQ-5D ($p <0.01$). However, other variables such as hospital stay, existing health condition and gender (being female) were associated with lower EQ-VAS scores ($p < 0.05$), that is, lower health status (Table 5).

Can quality of life predict outcomes?

The results of multiple regression analyses indicated that survivors' demographics, number of weeks since COVID-19 diagnosis and hospital stay were significant predictors of the extent of impact on QoL of the survivor ($p=0.001$) while the survivors' existing health condition was not a predictor (Tables 6). Inclusion of variables such as EQ-5D scores, family members' COVID-19 history, family members' gender and relationship to the survivor in the model predicted family reported outcomes ($p=0.001$) while family members' age, survivors' age, number of weeks since COVID-19 diagnosis, existing health condition and hospital stay were not significant predictors of QoL of family members

(Table 7). The multiple regression analyses confirmed that the QoL of family members/partner was more impacted than survivors, female family members were affected more than males, family members with a history of COVID-19 were affected more than those without and partners were affected substantially more than those of other relationships. In addition, the model predicted that younger survivors' functional behaviour (both physical and psychosocial) was more impacted by COVID-19.

Table 5 Correlation [†] matrix demonstrating the relationships between EQ-5D, FROM-16 and the participant demographics (n=735)

	EQ-5D score	FROM-16 score	EQ-VAS (n=733)	Survivor age (years)	Survivor gender	Survivor hospital stay for COVID-19	Survivor existing health condition	Number of weeks since COVID-19 diagnosis	Family member age (years)	Family member gender
EQ-5D score	1									
FROM-16 score	0.467**	1								
EQ-VAS (n=733)	-0.591**	-0.346**	1							
Survivor age (years)	-0.020	-0.118*	-0.075	1						
Survivor gender	0.077*	-0.024	-0.102*	0.064	1					
Survivor hospital stay for COVID-19	0.127*	0.073	-0.097*	0.143*	-0.091*	1				
Survivor existing health condition	0.093*	0.066	-0.104*	0.201**	0.036	0.134*	1			
Number of weeks since COVID-19 diagnosis	0.164*	0.029	-0.218	0.158*	0.032	0.097*	0.042	1		
Family member age (years)	-0.015	-0.077	-0.025	0.535**	0.066	0.034	0.145*	0.108*	1	
Family member gender	-0.030	0.031	0.032	-0.008	-0.507**	0.097*	0.050	-0.034	-0.113*	1

[†] Spearman's Rank; *p ≤ 0.05, **p ≤ 0.01, 2-tailed.

Table 6 Summary of survivors' characteristics predicting EQ-5D scores[*] (n=735)

	Unstandardised coefficients		Standardised coefficients		95% confidence interval levels for *B*					
Predictor	*B*	*Std. Error*	*Beta*	*p-value*	*Lower level*	*Upper Level*	*R^2*	*Adjusted R^2*	*F-test*	*p-value*
							0.058	0.051	8.907	0.0001
Survivor Age	-0.013	0.006	-0.076	0.043	-0.025	0.000				
Existing health condition	0.298	0.157	0.070	0.059	-0.011	0.607				
Hospital stay for COVID-19	0.644	0.181	0.131	0.0001	0.288	1.001				
Number of weeks since COVID-19 diagnosis	0.050	0.012	0.154	0.0001	0.027	0.073				
Male gender	-0.471	0.169	-0.101	0.005	-0.802	-0.139				

**Multiple regression; B=the slope of the line between the predictor variable and the dependent variable – the larger the number, the more spread out the points are from the regression line; F-test=degree of the linear regression model fitting the data; R^2 = how well the model fits the data; Males=1 and females =0; females are the reference group.*

Table 7 Summary of family member/partner characteristics predicting FROM-16 scores* (n=753)

	Unstandardised coefficients		Standardised coefficients		*95% confidence interval levels for B*					
Predictor	*B*	*Std. Error*	*Beta*	*p-value*	*Lower Level*	*Upper Level*	*R^2*	*Adjusted R^2*	*F-test*	*p-value*
							0.272	0.260	22.506	0.0001
EQ-5D score	2.019	0.134	0.495	0.001	1.757	2.282				
Age family member	-0.044	0.030	-0.073	0.144	-0.102	0.015				
Number of weeks since COVID-19 diagnosis	-0.064	0.043	-0.048	0.144	-0.149	0.022				
Male Family member	-1.357	0.587	-0.080	0.021	-2.510	-0.204				
Have you also had COVID-19?	1.138	0.524	0.071	0.030	0.109	2.167				
Relationship										
parent	-1.061	1.204	-0.033	0.379	-3.426	1.303				
sons and daughters	-3.243	1.108	-0.123	0.004	-5.419	-1.067				
brothers and sisters	-4.079	1.476	-0.090	0.006	-6.977	-1.180				
other	-2.728	1.827	-0.048	0.136	-6.314	0.859				
Survivor age	-0.040	0.032	-0.059	0.201	-0.103	0.022				
Survivor existing health condition	0.658	0.574	0.038	0.252	-0.468	1.785				
Survivor hospital stay for COVID-19	0.547	0.660	0.027	0.408	-0.749	1.842				

*Multiple regression; *B=the slope of the line between the predictor variable and the dependent variable – the larger the number, the more spread out the points are from the regression line; F-test=degree of the linear regression model fitting the data; R^2 = how well the model fits the data; Males=1 and females =0; females are the reference group.*

DISCUSSION

This study fills an important knowledge gap in measuring the impact of COVID-19 on the HRQoL of both the survivors and, importantly, their partners and family members. Health-related quality of life is defined as a person's perception of his/her physical, mental, social and overall well-being (8, 9). Therefore, its assessment embraces a wider view of the impact of COVID- 19.

This study has revealed that the pandemic has a major impact on lives of those who have survived the infection. The survey depended on the patient's self-report of the diagnosis of COVID-19 infection and did not specifically ask whether patients had had a COVID-19 positive test. However, further authentication of the diagnosis is given by both the patient and their relative having answered the survey. Pain and discomfort were the most frequently reported problem by COVID-19 survivors, followed by impact on their usual activities, anxiety and depression, affecting females to a greater extent. As the majority of COVID-19 survivors were in paid employment, being physically unwell might have impacted their usual activities or return to work. According to a review on return to work after critical illness (10), globally, a third of previously employed survivors after intensive care stays remained out of work after five years.

In the survey, COVID-19 survivors were asked whether they were 'already suffering from some existing chronic health condition (such as diabetes, heart disease, lung disease)' prior to the infection with COVID-19. Survivors with existing health conditions did not differ significantly from those without such conditions except for mobility and usual activities however, having an existing health condition was not a significant predictor of impact on the family member/partner's QoL. The survivor's QoL was impacted greatly irrespective of having a existing health condition as it was not clear predictor of EQ-5D scores in regression analysis. Hospitalised survivors reported greater impact on mobility, self-care and usual activities compared to those who had not been hospitalised. This survey did not ask respondents whether those hospitalised were admitted to ICU. So we are not able to draw any conclusion concerning the relationship of admission to ICU to later QoL.

The study also revealed a major impact on QoL of the survivors' partners and family members with partners being most impacted. Currently Minimal Clinically Important Difference (MCID) for

FROM-16 has not been published; however, MCID values for such questionnaires usually are approximately 10-20% of the total score range, and so we would expect the FROM-16 MCID to be approximately 3 to 6. If this is the case, the statistically significant differences reported would also be clinically significant. Nearly half of participating partners and family members also reported having had COVID-19. Although there were no significant differences between the family members with COVID-19 and those without across 10 of the 16 QoL items of FROM-16, eating habits, family activities, holiday, sleep, sex-life and work or study were impacted significantly more in those who had had COVID-19. Overall FROM-16 scores were higher for partners and family members with COVID-19 after adjusting for age, gender, relationship to survivor and the overall survivors' EQ-5D scores, thus indicating poorer QoL for family members with COVID-19 than for those without.

Most partners and family members reported being worried and frustrated, many reported sadness, inability to talk to someone and difficulty in caring for their loved ones. This is not surprising in a situation with constant media coverage with emphasis on high daily death rates, the fear of infecting loved ones, stigma due to community or family members blaming survivors for the spread of the illness, isolation of loved ones, inability of a family member to provide support, and prolonged recovery time (11). Such stressors have been implicated in the poor psychological and emotional health of survivors and their family members (11-14).

Family members reported an impact on sexual life as a result of their relative's COVID-19 and this impact was higher in males and in family members who has also contracted COVID-19. Two-thirds of family members were either spouses or partners, who could have experienced these difficulties because of the contagious nature of COVID-19 and because of post survival symptoms. Moreover, physical illness in partners has a significant impact on marital relationships, contributing to marital dissatisfaction and likelihood of later divorce (15). Over half of partners and family members reported impact on holidays and nearly half reported an increase in expenses due to their relative's COVID-19.

One of the key findings of this study is the evidence that in survivors in whom the COVID-19 onset was more than 12 weeks ago, there was still a major persisting impact on QoL across all domains in both survivors and family members. This provides further evidence of the severe impact of post-acute COVID-19 (“Long COVID”) and “Chronic COVID” (16). According to NICE, the term ‘long COVID’ “ is commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more)” (17). The term ‘Persisting’ refers to the continuity of the impact of COVID-19 on survivor’s health since the onset of COVID-19 infection.

Interestingly, of the patients who participated, most (76.6%) were women, as found in other surveys(18); however, there was a higher proportion of men among participating family members (66.5%). This may be because the majority of COVID-19 social media support groups have been initiated by women (patients), and the most convenient family person to ask to participate might be their partners (mostly male).

Comparison with other studies

Chinese survivors of COVID-19 reported lower HRQoL with significant impact on their physical and psychological health, one month after recovery (19). Our study has shown a major impact not only on the HRQoL of survivors of COVID-19 but also on their partners and family members. This is consistent with the findings of Golics et al. (2, 20) that multiple elements of family members' lives can be affected by a relative's illness including emotional, financial, family relationships, education and work, leisure time, and social activities.

Our study has shown that most (87%) survivors had COVID-19 for more than 4 weeks, and 64% more than 12 weeks indicating that survivors continued to remain unwell for long periods of time, due to post-viral symptoms or ‘long COVID’. This is in contrast to a UK COVID-19 symptom study (21), where only 10% of COVID-19 positive survivors remained unwell at three weeks, and a small proportion for more than three months. An online survey of British doctors in August 2020 revealed that many were being treated for long term COVID-19 symptoms such as chronic fatigue, muscle weakness, loss of sense of smell, and concentration difficulties (22)

In our study 69% COVID-19 survivors reported feelings of anxiety and depression, much higher than the 43.1% reported by Ma Y-F et al. (9) in clinically stable patients with COVID-19. Previous studies of Severe Acute Respiratory Syndrome (SARS) revealed the persistence of depression in patients up to 30 months after discharge from hospital (23, 24).

Several studies have shown the impact of COVID-19 on sleep patterns of survivors, with an increase in prevalence of insomnia (25-27). We do not know whether the sleep patterns of survivors in our study were also impacted, since EQ-5D does not include such an item. However, in our study 69 % of partners and family members experienced problems with sleep, and 32% reported that their sleep was impacted "a lot".

The total mean domain scores for FROM-16 in this study were 6.12 (Emotional) and 8.88 (Personal and Social Life) which are higher than the mean domain scores reported by Golics et al. (5) (Emotional=5.6; Personal and Social Life=6.7) on the impact of patients' chronic disease on family members across 26 medical specialties. Another study (4) reported the mean domain scores of family members of patients with cancer as Emotional=4.7 and Personal and Social Life=7.1. In a FROM-16 study on family members of patients with urinary stone disease, family members were not impacted much by their relative's disease, however they reported a slightly greater degree of change in the 'emotional' domain compared with the 'personal and social life' domain (28). This indicates that family members of COVID-19 survivors suffered more than family members of patients with other severe chronic diseases.

Strengths and Limitations.

This study to our knowledge is the first global study to explore the impact of COVID-19 on both survivors and also their family members/partner. Other strengths include the large sample size, heterogenous population and use of validated tools to assess QoL impact. The study has demonstrated use of the FROM-16 questionnaire for studying the effects of a pandemic on family members of an infected person.

This study has several limitations. Firstly, it suffers from considerable selection bias as only those COVID-19 survivors and family members who could access the internet and were active on social media completed the online questionnaires, limiting generalisability of the study findings. It is also possible that people who experienced persisting symptoms may have been more likely to have participated in the study. This survey was conducted internationally in the English language. Although FROM-16 is available to researchers in several languages, our full survey documents and the participant information sheet were only available to the participants in the English language, and in the survey FROM-16 was also only provided in English. Participants could only take part if they could understand all of the documentation. The ability of some respondents to read and understand English may have been limited, but we are not able to assess this. However, during the development of, in particular, FROM-16, the following issues were considered as part of its conceptualisation and development in order to improve its universality and translatability:1) applying readability to the level of understanding of a 12 year old; 2) formatting of the items into short and complete sentences of about six words to enhance clarity of meaning; 3) ensuring ease of understanding to allow future cross-cultural adaptation, facilitating universality and translatability. Although we did not develop the EQ-5D, that questionnaire was also designed to be as universally understandable as possible. Concerning the wider survey questions, we took several steps in the development of the survey to ensure maximum comprehensibility:1) We ensured that the readability was acceptable to a 12-year-old standard; 2) We carried out an international pilot including participants for whom English was not their first language and made adjustments accordingly; 3) The survey was reviewed by our patient study research partners.

Secondly, the study, being cross-sectional, cannot establish causal relationships among the study variables. Because of the nature of the study, we could not collect any baseline measurements (pre-COVID-19 measurements). We are, therefore, not able to differentiate between the effect of COVID-19 infection or of a pre-existing physical or mental state. However, only 30.9% of respondents had any existing health condition, and therefore this limitation only refers to this small proportion of respondents. In addition, as all the covariates in the study were self-reported, data on hospitalisation and medical problems could be inaccurate and is a potential limitation(29). This study does not have a control group but in healthy volunteers in the UK, mean EQ-5D scores were EQ-VAS = 82.75, Mobility = 0.18, Self-Care = 0.04, Usual Activity = 0.16, Pain/Discomfort = 0.33, Anxiety / Depression = 0.20 (30). In contrast, COVID-19 survivors (47.1 % of survey respondents were from the UK) in our study had mean scores of EQ-VAS = 55.83, Mobility = 1.59, Self-Care = 1.23, Usual Activity = 2.06, Pain / Discomfort = 1.93, Anxiety / Depression = 1.84. This suggests that overall HRQoL was highly impaired in the COVID-19 survivors across all domains. Furthermore, the study was carried out between June and August 2020 when the severity of the pandemic varied among different countries. Therefore, the study results may have been influenced by the specific local and governmental measures in place at the time. It is likely that participants will have been living under different government restrictions, thereby possibly influencing responses to the questionnaires. However, because of the complexity of the international situation, we are not able to account for this. Although formal cultural adaptation of the survey questionnaire was not carried out, we endeavoured to ensure maximum understandability and acceptability. It should be noted that the questions asked are mostly universal in nature and do not refer to culturally specific practices such as semantic differences. However, despite these limitations, the study has provided a rapid overview of survivors' and their family members' HRQoL and revealed evidence of the substantial persisting effect on QoL of survivors and a major secondary impact on the lives of partners and family members. This information can be used to inform policymakers about the health needs of these individuals and may encourage the development of tailor-made support services.

Implications for clinicians and policymakers

Our results have shown how the impact of COVID-19 on one family member can have a domino effect on other family members, especially those close to them such as partner, parents and children. It is important to understand the needs of these impacted family members and survivors to ensure the overall wellbeing of the family unit. Based on the findings of this study, policymakers should consider developing and commissioning the following support services for survivors and family members:

Post COVID-19 clinics: Survivors reported pain and discomfort even after 12 weeks of COVID-19, indicating that tailored services to deal with such symptoms are important to help survivors suffering with long term sequelae. Survivors with post-COVID-19 complications should be heard and treated. Although such clinics have been started in a few countries, there is a considerable need for such initiatives globally.

Needs-based mental health counselling: Most family members and survivors reported being depressed and worried. It is imperative to further develop care services to ensure the mental wellbeing of survivors and their family members.

Physical activity and rehabilitation services: Most survivors have reported pain and discomfort and an inability to do their normal activities. Rehabilitation clinics could provide emotional and physical support to physically and emotionally drained survivors and their family members to enable their return to normal routines.

Social support services: Patients with COVID-19 are from diverse backgrounds and therefore will benefit from culturally and socially appropriate support. Financial assistance is particularly important for those who do not have health insurance to cover COVID-19 expenses.

Patient support groups/local support groups for COVID-19 survivors and family members: Local support groups could be used in primary care settings and can help by significantly combating isolation and the disability the study has identified that occurs in COVID-19 survivors and their family members/partners. This could in turn have health economic benefits by possibly reducing long-term utilisation of mental health services. Similar approaches have been successful, for example in supporting people with myalgic encephalitis.

Future research and recommendations

Although this study provided an overview of the impact of COVID-19 on survivors' partners and family members, it was not designed to identify causal relationship. Future longitudinal studies are needed to understand the long-term impact of COVID-19. As COVID-19 is still a major challenge, with people experiencing 'long COVID', there is a need for further research including long term studies to better understand 'long COVID' and its impacts on survivors and family members. However, the way the participants were recruited for the current study does not allow us to have access to follow-up data from this cohort. We were unable to measure the impact of COVID-19 on sleep and sex-life of survivors, future studies should measure such impacts.

CONCLUSION

Survivors of COVID-19 report a major persisting impact on their QoL with many feeling unwell beyond 12 weeks. This indicates a demand for a holistic support system that is sensitive to their needs. Moreover, the QoL of partners and family members is also severely impacted, demonstrating the importance of investigating disease impact on family QoL. The establishment of services to provide support to family members of survivors and patients in general is therefore a key consideration in the future management of COVID-19. Although the recruitment method used inevitably leads to some degree of selection bias which in turn may dilute the generalisability of the study findings, the central conclusions of this study, that COVID-19 has a profound and long-lasting impact on survivors and their family members continue to remain valid.

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Competing interests: All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: no support from any organisation for the submitted work; RS and SJN declared no competing interest, AYF and SS are joint copyright owners of Family Reported Outcome Measure (FROM-16). JRI reports personal fees from UCB Pharma, personal fees from Novartis, personal fees from Boehringer Ingelheim, personal fees from Kymera Therapeutics, personal fees from Viela Bio, personal fees from UpToDate, personal fees from Editor of British Journal of Dermatology, outside the submitted work; in addition, JRI is co-copyright holder of the Hidradenitis Suppurativa Quality of Life (HiSQOL) score. FMA reports grants and personal fees from Janssen, personal fees from Abbvie, personal fees from Lilly Pharmaceuticals, personal fees from L'Oreal, personal fees from LEO Pharmaceuticals, personal fees from UCB, outside the submitted work.

Author contributions: RS primarily carried out the study. wrote first drafts and revised all documentation. SS and AYF equally contributed to the design and supervision of the study and revised all study documentation and the manuscript. FMA, JRI and SJN provided advice during the study and helped revise study documentation. FMA, JRI and SJN reviewed the manuscript. The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

Public and Patient Involvement (PPI): Twenty members of the public, including some work colleagues, participated in the pilot study. Some had experience of having COVID-19 patient in their family. The study sociodemographic questions were extensively modified following the outcome of the pilot study. The 'patients and family member group' consisting of two patients and one family member, were involved as study research partners. This group was involved in reviewing the study protocol, other related documents and the manuscript.

Ethical approval: Ethics approval was granted by the Cardiff University School of Medicine Research Ethics Committee (SMREC 20/60).

Data sharing: This paper does not report a trial. If requested, we are happy to share our data.

Transparency statement: The lead author RS affirms that this manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned (and, if relevant, registered) have been explained.

Dissemination to participants and related patient and public communities: The summary of the results will also be disseminated by social media using the same methods as used for recruiting participants and made accessible to public and patients through the Cardiff University FROM-16 website page

Figure legends

Figure 1 COVID-19 survivor response to EQ-5D-3L (n=735)

Figure 2 Partner and family member response to FROM-16 items (n=735)

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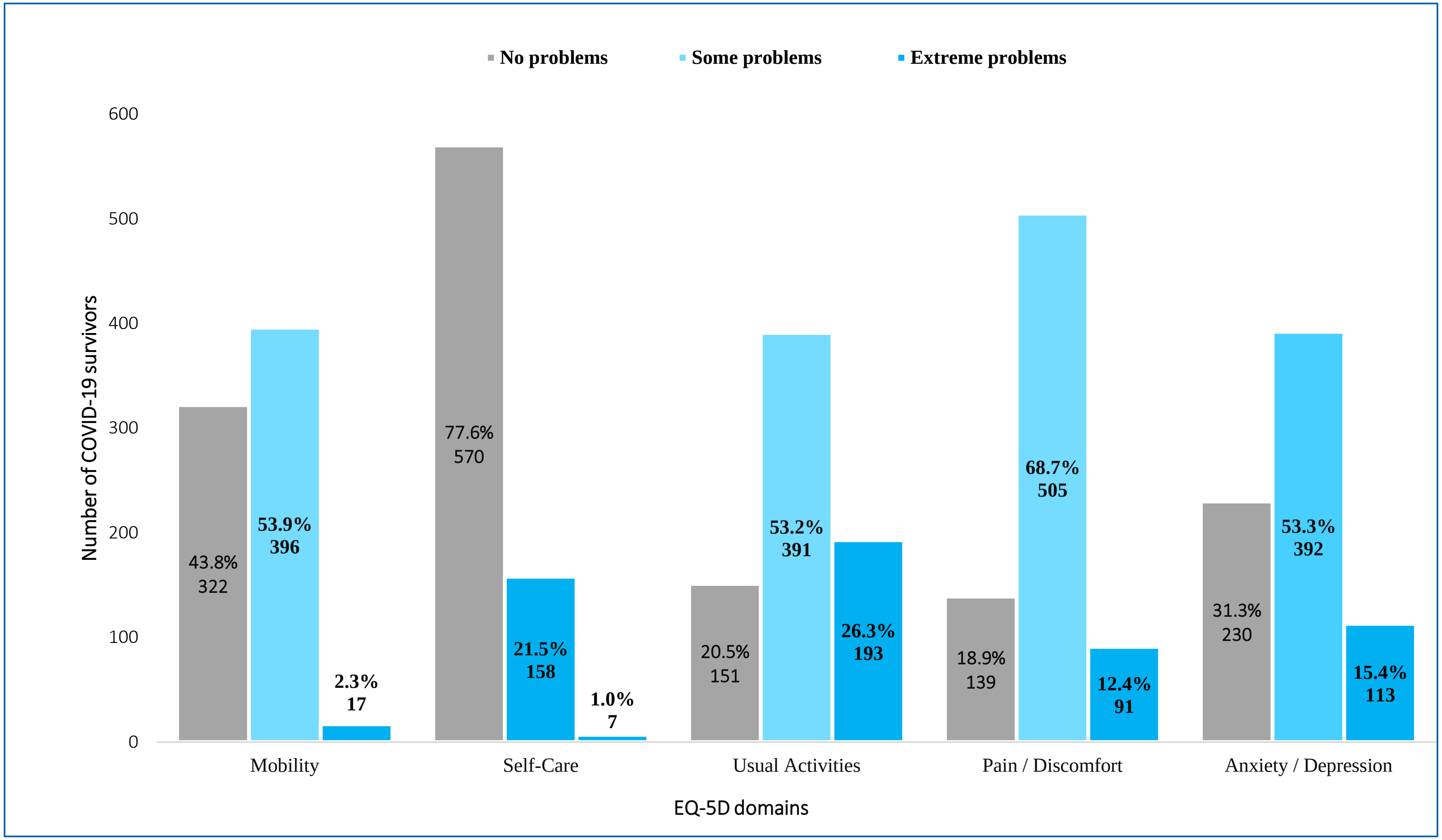
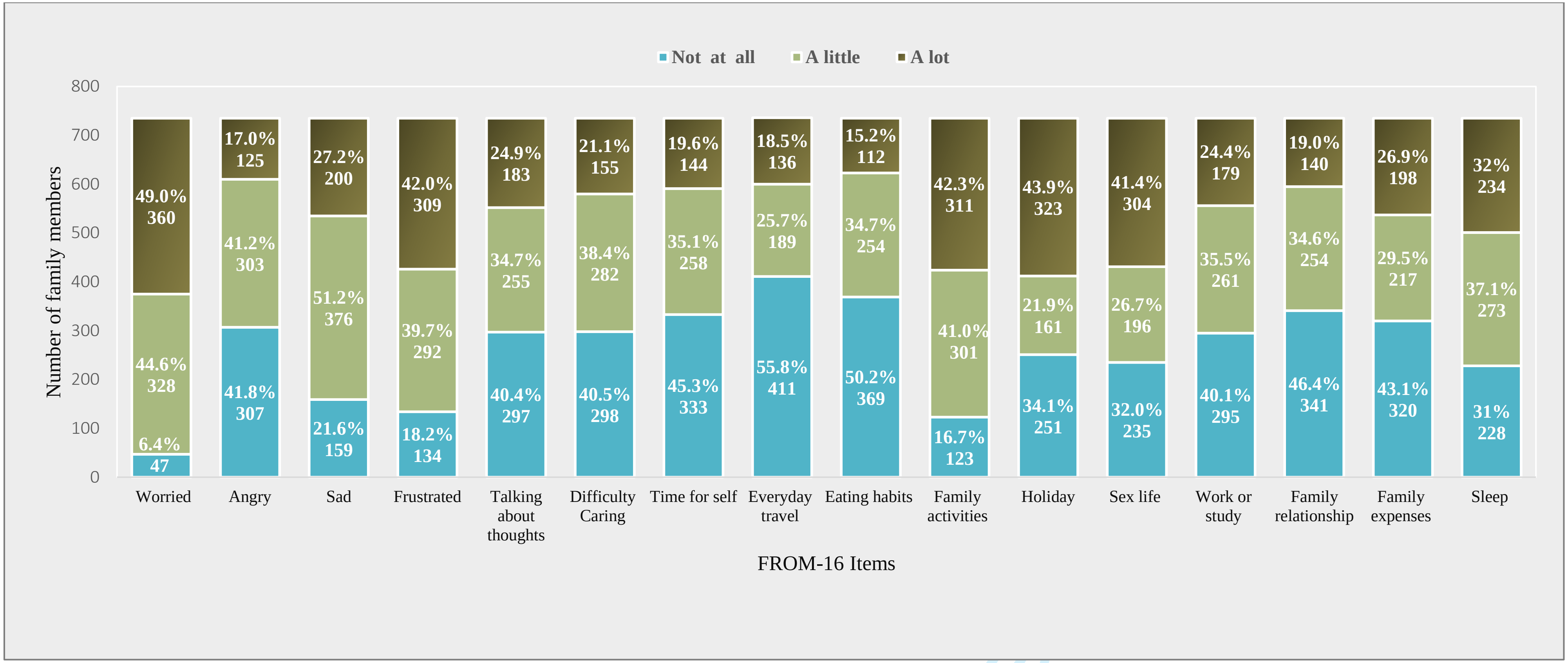
Figure1 COVID-19 survivor response to EQ-5D-3L (n=735)




■ Not at all
■ A little
■ A lot
800
700
600
500
400
300
200
100
0
Number of family members
Worried: 6.4% 47; 44.6% 328; 49.0% 360
Angry: 41.8% 307; 41.2% 303; 17.0% 125
Sad: 21.6% 159; 51.2% 376; 27.2% 200
Frustrated: 18.2% 134; 39.7% 292; 42.0% 309
Talking about thoughts: 40.4% 297; 34.7% 255; 24.9% 183
Difficulty Caring: 40.5% 298; 38.4% 282; 21.1% 155
Time for self: 45.3% 333; 35.1% 258; 19.6% 144
Everyday travel: 55.8% 411; 25.7% 189; 18.5% 136
Eating habits: 50.2% 369; 34.7% 254; 15.2% 112
Family activities: 16.7% 123; 41.0% 301; 42.3% 311
Holiday: 34.1% 251; 21.9% 161; 43.9% 323
Sex life: 32.0% 235; 26.7% 196; 41.4% 304
Work or study: 40.1% 295; 35.5% 261; 24.4% 179
Family relationship: 46.4% 341; 34.6% 254; 19.0% 140
Family expenses: 43.1% 320; 29.5% 217; 26.9% 198
Sleep: 31% 228; 37.1% 273; 32% 234
FROM-16 Items

Section/Topic	Item #	Recommendation	Page No	Relevant text from the manuscript
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	2	Abstract
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	2	Abstract page 1
Introduction				
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3	Introduction- paragraph 1, 2
Objectives	3	State specific objectives, including any prespecified hypotheses	4	Introduction- paragraph 3
Methods				
Study design	4	Present key elements of study design early in the paper	4, 5	Methods
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4-5	Methods-setting/ participants / procedure
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	5	Method-procedure
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	6	Methods -outcome /exposure/Covariates/missing data
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	6	Methods-Measurements tools
Bias	9	Describe any efforts to address potential sources of bias	*7, 14-15*	Methods and Regression
Study size	10	Explain how the study size was arrived at		Study Size = Exploratory
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	7	Statistical analysis
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	7	
		(*b*) Describe any methods used to examine subgroups and interactions	7-17	Statistical analysis and Tables 1-7
		(*c*) Explain how missing data were addressed	7	There were no missing data
		(*d*) If applicable, describe analytical methods taking account of sampling strategy		Exploratory
		(*e*) Describe any sensitivity analyses		Not applicable

Results				
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7	Results section
		(b) Give reasons for non-participation at each stage		Not applicable
		(c) Consider use of a flow diagram		Not applicable
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7-8	Table 1 descriptive analysis
		(b) Indicate number of participants with missing data for each variable of interest		NA (no missing data)
Outcome data	15*	Report numbers of outcome events or summary measures	7	Results and Tables/Figures
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (e.g., 95% confidence interval). Make clear which confounders were adjusted for and why they were included	7-17	Results section-Table 3, 4 and 5. Multiple regression Tables 6 and 7
		(*b*) Report category boundaries when continuous variables were categorised		Not Applicable
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period		Not Applicable
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	10-13	Results – Sub group analysis-male /female; hospitalise for COVID-19/not hospitalised ; Pre-existing health condition / No pre-existing health condition; partner and Family member 's with COVID / Partner and family not having COVID Tables 3 and 4
Discussion				
Key results	18	Summarise key results with reference to study objectives	18-19	16-17
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	20	Strengths and Limitation section
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	20-21	Strengths and limitation / comparison with other studies

Generalisability	21	Discuss the generalisability (external validity) of the study results	20	Strengths and limitations section
Other information				
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based.	24	Funding section

STROBE 2007 (v4) Statement—Checklist of items that should be included in reports of *cross-sectional studies*

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.