



Psychological distress experienced by parents caring for an immunosuppressed child during the COVID-19 pandemic

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ABSTRACT

The COVID-19 pandemic has proved unique in both its unpredictability and the extent to which it has continued to impact on daily life since March 2020. Among the immunosuppressed population the challenges of the COVID-19 pandemic are cumulative to the ever-present challenges of living with a long-term condition.

This prospective longitudinal study explored patterns of concern experienced by 467 British parents caring for an immunosuppressed child during the first 2 years of the COVID-19 pandemic and related this to parental mental wellbeing.

Most parents slowly adapted or were resilient to the ever-changing stressors of the COVID-19 pandemic. However, 12% experienced high levels of concern throughout the first 2 years of the pandemic. This group was also more likely to report emotional mental health problems towards the end of this period.

The experience of emotional mental health problems among parents caring for an immunosuppressed child was related to low household income, single parenting, difficult access to greenspace, and higher level of exposure to COVID positive cases and COVID restrictions (North of England).

Parents reported that optimism, reduction of isolation, and support promoted coping and management of the challenges of the COVID-19 pandemic. More reliable COVID information and periodic medical-condition-specific guidance would have been appreciated.

These findings can increase clinical awareness of high-risk parental groups and make an important contribution to the planning of appropriate targeted psychological family interventions.

1. Introduction

In the past few years there have been several studies that described the negative impact of the COVID-19 pandemic on parental mental health and wellbeing (Dawes and May, 2021), with some parental subgroups showing greater vulnerability to the psychological impacts of the COVID-19 pandemic (Pierce et al., 2020; Ellwardt and Präg, 2021). For instance, the COVID-19 Social Study (Mak et al. preprint 2021) described the increase in depressive and anxiety symptoms among their sample of informal caregivers. An unknown percentage of this sample were parents caring for a child with a long-term condition.

Parents of children living with a long-term condition have increased

caregiving burden as they not only manage familial responsibilities but also accommodate the nutritional, physical, social, emotional, medical and financial needs associated with the long-term condition of their child (Dudeney et al., 2017). In the beginning of the COVID-19 pandemic around 100000 British children and young people living with a long-term condition were identified by health professionals as being clinically vulnerable to severe medical complications if infected with SARS-CoV-2 (Gibbs, 2020). This group of vulnerable children and young people was for a large part made up of children who due to their medication or health condition were immunosuppressed, and therefore, in general, at high risk for bacterial and viral infections (Memoli et al., 2014). For the parents of these children, the COVID-19 pandemic

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presented an unpredictable life event cumulative to the challenges of managing their child's long term health condition. New normalities followed each other in quick succession adding the strain of repeated adaptation. Information on the psychological impact of the COVID-19 pandemic on this parental sub-population remains scarce.

Based on studies exploring human psychological response to adverse life events [Bonanno et al. \(2010\)](#) have developed their theory of psychological resilience. This theory explains how the coalescence of risk and resilience factors in a cumulative manner determines whether psychological response to adversity follows the resilient, recovery, delayed distress, or enduring concern and distress pathway. They have shown that this theory can be applied to individuals exposed to major disease outbreaks such as the 2003 SARS epidemic in Hong Kong ([Bonnano et al., 2008](#)).

The main aim of the here described study was to determine if the theory of psychological resilience could be applied to British parents caring for an immunosuppressed child during the first 2 years of the COVID-19 pandemic. Over the past couple of decades there has been some variation in the outcome measures used in psychological resilience studies ([Galatzer-Levy et al., 2018](#)). The focus of our study has been on parental concern, the worries British parents reported during the first 2 years of the COVID-19 pandemic while caring for their immunosuppressed child. We further endeavoured to describe some of the risk and resilience factors that influenced the parental concern and distress pathways. Research initiated during the first 3 months of the COVID-19 pandemic has indicated some of the risk factors related to adult psychopathology, including SARS-CoV-2 infection, financial difficulty, loss of paid work, difficulties acquiring medication, difficulties accessing food, and threats to personal safety ([Westrupp et al., 2021](#); [Wright et al., 2021](#)). It remains to be explored if these factors affect longer term concern and distress pathways of parents caring for an immunosuppressed child. For intervention purposes we believe it is crucial to learn which concern and distress pathways may increase risk of future psychopathology so as to facilitate targeted support, hence we also determined the association between parental concern pathways and emotional mental wellbeing.

2. Methods

This study is part of a wider research project, the ImmunoCOVID-19 study, investigating the daily clinical and life experiences of immunosuppressed paediatric patients and their carers recruited from 46 UK hospitals ([Shanauk et al., 2021](#); [Chappell et al., 2022](#)). The Leeds NHS Research Ethics Committee provided ethical approval to this research project (IRAS 281544). All participants completed informed consent for both weekly the ImmunoCOVID-19 surveys administered between March 2020 and April 2022 and a mental wellbeing survey administered in November/December 2021, January/February 2022, and March/April 2022. All procedures contributing to this work comply with the latest version of the Helsinki Declaration.

2.1. Participants

2856 British parents caring for an immunosuppressed child who was eligible to apply for the 2019 NHS children's influenza programme (Public Health England, 2020) were referred to the ImmunoCOVID-19 study by their child's NHS clinical specialist team. Recruitment commenced across 46 UK hospitals between March and July 2020 and 1631 (57.1%) of the parents consented to participate in weekly online surveys assessing daily clinical and life experiences of these immunosuppressed paediatric patients and their carers. As described by [Chappell et al. \(2022\)](#) the parents who consented to the weekly online survey of the ImmunoCOVID-19 study were more likely to live in the South of Britain and care for younger children than the parents who did not consent to participate in the ImmunoCOVID-19 study. In July 2021, the 1021 parents who regularly completed the weekly survey of the

ImmunoCOVID-19 study were invited to participate in a mental wellbeing extension study. 467 parents consented (45.7%) and were asked to complete a mental wellbeing online survey in November/December 2021, January/February 2022, and in March/April 2022. These 467 parents were not significantly different in gender or geographical location nor did their child's characteristics (age & gender) differ to the full 1021 sample of parents regularly completing the ImmunoCOVID-19 weekly survey (see [Table 1](#)). The experiences of these 467 parents are described in this paper.

2.2. Measures

The children's clinical (diagnosis/medication) and demographic (age, gender) information was assessed at baseline (March–July 2020). As part of the weekly ImmunoCOVID-19 survey administered between March 2020 and April 2022, parental concern was assessed on a scale of 0 [not worried] to 10 [extremely worried] with the question “how worried are you about coronavirus affecting your child?” and the open-ended question “Is there anything that you are particularly worried about that you would like to share?”. Parental demographic/household information (gender, age, geographical location, rural/urban, green space, household income, household composition, and employment) were collected in September 2021. Parental mental wellbeing was assessed with the 21-item self-report Depression and Anxiety Stress Scales (DASS—21; [Lovibond and Lovibond, 1995](#)) in November/December 2021, January/February 2022, and in March/April 2022. This scale has 3 domains (depression, anxiety, and stress), each consisting out of 7 items. Answer categories to the 21-items range from 0, ‘did not apply to me at all’, to 3, ‘applied to me very much’/‘most of the time’, leading to a minimum domain score of 0 and a maximum domain score of 21. The domain scores for depression and anxiety were taken into account when determining the parent's emotional mental health status in the currently described project. The recommended cut-off scores of 10 or higher on the depression domain and 8 or higher on the anxiety domain were used to indicate if a parent experienced depressive/anxiety symptoms (yes/no). A combined dummy score was also created to indicate if the parent experienced anxiety and/or depressive symptoms (PEMH).

2.3. Quantitative analysis

In a previous publication we touched on the parental concern experienced by parents included in our sample during the first 18 months of the COVID-19 pandemic ([Driessens et al., 2022](#)). In this study we expanded the quantitative analyses in two ways (1) extended the observation period from first 78 weeks of the pandemic to first 105 weeks of the pandemic, and (2) explored the association between long-term parental concern pathways and PEMH.

Within the longitudinal parental concern data collected weekly from 467 parents over the first 105 weeks of the pandemic we identified the best fitting homogeneous latent parental concern trajectories model using the Latent Class Growth Analysis (LCGA) procedure included in the PROC TRAJ extension ([Jones et al., 2001](#)) of the SAS9.4 software (SAS Institute INC, Cary NC). Following Proc Traj's missing-at-random assumption, individuals with missing data were assigned to their most likely latent parental concern pathway ([Andruff et al., 2009](#)). Additional details of the procedure followed can be found in our previous publication ([Driessens et al., 2022](#)).

Furthermore, we determined the influence of the time-stable PEMH covariate on parental concern trajectory by expanding the PROC TRAJ syntax with the RISK statement and also verified the association between PEMH and parental concern using Mantel-Haenszel Test of Linear Association.

Table 1
Demographic information parents caring for immunosuppressed child.

	Invited parents	Participating parents	resilient	Recovering medium concern	Recovering high concern	Chronic high concern
Gender parent (female)	89.3%	395 (89%)	80 (85.1%)	149 (88.2%)	119 (90.8%)	47 (94.0%)
Age parent						
<30		2 (0.5%)	1 (1.1%)	0	1 (0.8%)	0
30–40		100 (22.7%)	24 (25.5%)	33 (20.5%)	27 (20.9%)	16 (32.7%)
41–50		237 (53.7%)	48 (51.1%)	87 (54.0%)	77 (59.7%)	26 (53.1%)
50+		102 (23.1%)	21 (22.3%)	41 (25.5%)	24 (18.6%)	7 (14.3%)
Region						
Scotland	10.6%	54 (12%)	16 (16.7%)	18 (10.5%)	15 (11.5%)	5 (9.8%)
Northern Ireland	0.1%	1 (0.2%)	0	0	1 (0.8%)	0
Wales	2.3%	15 (3.3%)	4 (4.2%)	3 (1.8%)	6 (4.6%)	2 (3.9%)
North England	25.8%	96 (21.4%)	14 (14.6%)	37 (21.6%)	27 (20.6%)	18 (35.3%)
Mid England	19.4%	75 (16.7%)	18 (18.8%)	23 (13.5%)	24 (18.3%)	10 (19.6%)
South England	41.8%	208 (46.3%)	44 (45.8%)	90 (52.6%)	58 (44.3%)	16 (31.4%)
Urbanization						
Rural		56 (12.7%)	13 (14.0%)	21 (12.6%)	19 (14.6%)	3 (6.0%)
Semi-rural		149 (33.9%)	24 (25.8%)	61 (36.5%)	42 (32.3%)	22 (44.0%)
Urban		235 (53.4%)	56 (60.2%)	85 (50.9%)	69 (53.1%)	25 (50.0%)
Greenspace						
Difficult access		5 (1.1%)	1 (1.1%)	1 (0.6%)	2 (1.5%)	1 (2.0%)
Sometimes easy/difficult		20 (4.5%)	3 (3.2%)	4 (2.4%)	8 (6.1%)	5 (10.0%)
Easy access		420 (94.4)	90 (95.7%)	165 (97%)	121 (92.4%)	44 (88.0%)
Household composition						
Single parent with children		62 (14.3%)	19 (20.2%)	21 (13.0%)	12 (9.2%)	10 (20.0%)
Couple with children		344 (79.1%)	70 (74.5%)	129 (80.1%)	109 (83.9%)	36 (72.0%)
Couple, family, children		29 (6.7%)	5 (5.3%)	11 (6.8%)	9 (6.9%)	4 (8.0%)
Employment parent						
Fulltime		157 (36.5%)	35 (38.0%)	61 (38.4%)	48 (36.9%)	13 (26.5%)
Parttime		178 (41.4%)	12 (13.0%)	29 (18.2%)	34 (26.2%)	20 (40.8%)
Not working		95 (22.1%)	45 (48.9%)	69 (43.4%)	48 (36.9%)	16 (32.7%)
Household income						
Lower than £29500		80 (18.7%)	15 (16.3%)	26 (16.5%)	22 (17.1%)	11 (22.5%)
Around £29500		74 (17.3%)	59 (64.1%)	110 (69.6%)	79 (61.2%)	26 (53.1%)
Higher than £29500		274 (64%)	18 (19.6%)	22 (13.9%)	28 (21.7%)	12 (24.5%)
Number of children						
1		113 (27.2%)	25 (28.2%)	42 (27.8%)	30 (23.4%)	17 (35.4%)
2		205 (49.3%)	44 (49.4%)	75 (49.7%)	66 (51.6%)	20 (41.7%)
3+		97 (23.5%)	20 (22.4%)	34 (22.5%)	32 (25%)	11 (22.9%)
Gender child (female)	55.1%	226 (57.7%)	55 (59.1%)	70 (53.4%)	72 (58.5%)	29 (64.4%)

2.4. Qualitative analysis

Parental responses to the weekly open-ended question “Is there anything that you are particularly worried about that you would like to share?” provided a parental concern narrative for each parent throughout the two years of the COVID pandemic. Drawing on these individual concern narratives, a summary ‘case profile’ was created for each of the latent parental concern pathways discovered in the quantitative analysis. Each ‘case profile’ represented the changes and continuities experienced during the first 105 weeks of the COVID pandemic by the parents grouped in that specific latent parental concern pathway. An interpretative phenomenological analysis approach was adopted (Smith and Shinebourne, 2012) to offer insight into shared perspective of parents traveling on the same concern pathway and to shed light on the multiple different perspectives on the challenges posed by the COVID-19 pandemic of parents included in the different concern pathways. Initial analysis was performed by CD. The initial findings were cross-compared by second coder, LM. The findings were further refined through discussion with the research team. The analysis presented here covered a subset of the patterns of code that emerged, namely the risk and resilience factors impacting the different parental concern pathways.

3. Results

3.1. Characteristics of the participants (Table 1)

The parents of immunosuppressed children who participated in this study were most commonly middle-aged mothers sharing the care for

two children with a partner. Most families lived in an urban area in the South of England and had easy access to green space during the COVID-19 pandemic. The household income on average was higher than £29500 and most parents completing the surveys were employed part-time.

3.2. Parental concern pathways

The 467 parents of immunosuppressed children provided in total 28998 weekly observations with a median of 71 weekly observations per parent. Following the criteria set forth by Nagin (2005) a four-trajectory model (Fig. 1) was considered the best fit for the parental concern data as this model represented four groups with group sizes >5% of the sample size. This model had the smallest negative number of Bayesian Information Criterion (BIC = -49008) and Akaike Information Criterion (AIC = -48975) when compared to one, two, and three trajectory models. In addition, the average posterior probability fulfilled the criteria of being >0.7 for each of the four groups (respectively 0.9974, 0.9943, 0.9942, 0.8731).

The four concern pathways represent (1) resilient parents (23.8%) with transient levels of concern at the beginning of the pandemic but stable low concern throughout the rest of the pandemic with small increases in concern levels in January 2021 and February/March 2022 (2) recovering-from-medium-levels-of-concern parents (33.0%) with medium levels of concern at the start of the COVID-19 pandemic and some adaptation over the next 24 months with small increases in concern levels in January 2021 and February/March 2022 (3) recovering-from-high-levels-of-concern parents (31.3%) with high levels of concern at the start of the COVID-19 pandemic and steady small adaptation over

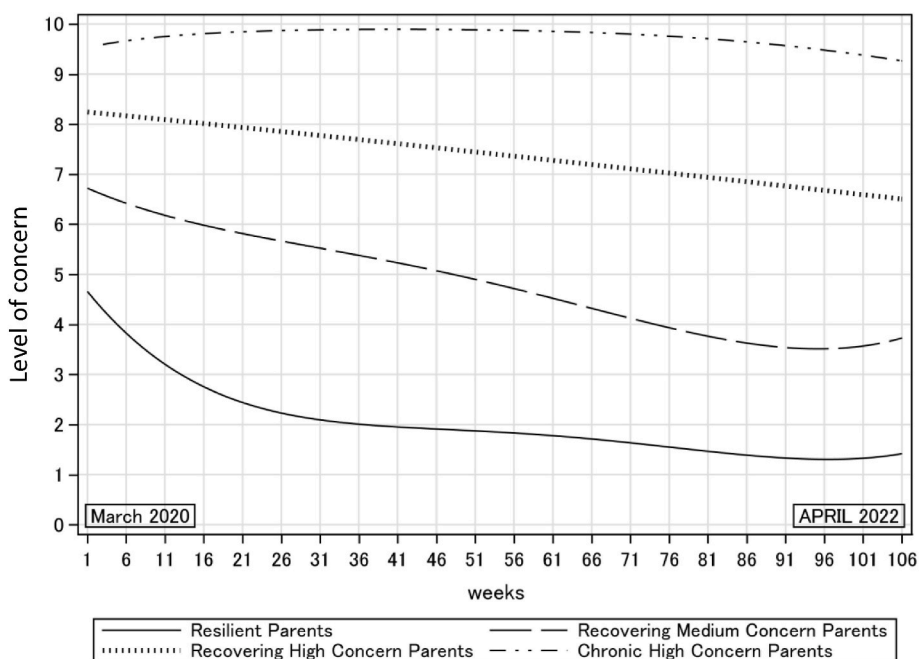


Fig. 1. Level of parental concern during the first 2 years of the COVID-19 pandemic.

the next 24 months (4) chronic concern parents (12%) who experienced high levels of concern throughout the COVID-19 pandemic.

3.3. Association parental concern pathway and PEMH

Of the 467 parents caring for an immunosuppressed child during the COVID-19 pandemic 149 completed all three mental wellbeing assessments in Nov/Dec 2021, Jan/Feb 2022, and March/April 2022. 98 parents completed two of the three mental wellbeing assessments and 105 parents completed one of the three mental wellbeing assessments. 115 parents did not respond to the mental wellbeing survey. Male parents were less likely to respond to the mental wellbeing questionnaire than female parents.

In November/December 2021 7.9% of the parents caring for an immunosuppressed child reported emotional mental health problems. This reduced to 5.4% by January/February 2022 and 4.9% by March/April 2022. The Mantel-Haenszel test of linear association indicated at all three timepoints that with an increase in parental concern the proportion of parents experiencing emotional mental health problems (PEMH) significantly increased (Table 2 Nov/Dec Mantel-Haenszel Test of Linear Association = 7.23, $p = 0.065$; Jan/Feb Mantel-Haenszel Test of Linear Association = 13.76, $p = 0.0032$; Mar/Apr Mantel-Haenszel Test of Linear Association = 5.00, $p = 0.17$).

The participants in the ImmonuCOVID-19 study showed selective drop-out (non-response) due to psychological concern and distress. When we compared this selective drop-out across the parental-concern pathways we noticed that the resilient, recovering, and chronic concern groups displayed respectively 2.33%, 13.75%, 16.13%, and 38.89% selective drop-out. The Mantel-Haenszel Test of Linear Association indicates that with an increase in parental concern there is a significant increase in non-response (Mantel-Haenszel Test of Linear Association = 14.04, $p = 0.0028$). The trend of number of parents experiencing emotional mental health problems (PEMH) in relation to parental-concern pathways would probably have been more pronounced had this selective drop-out not been present.

Using the resilient parents as a reference group we examined the association between PEMH and parental concern pathway in the latent growth analysis and found that compared to the resilient parents the recovering-from-high-concern-level parents ($p = 0.016$) and the

Table 2

Mental wellbeing of parents caring for an immunosuppressed child.

	Total group	Resilient	Recovering medium concern	Recovering high concern	Chronic high concern
20M					
Anxiety	19 (4.0%)	1 (0.9%)	7 (4.5%)	6 (4.1%)	5 (8.9%)
Depression	32 (6.9%)	3 (2.7%)	10 (6.5%)	13 (8.9%)	6 (10.7%)
PEMH	37 (7.9%)	3 (2.7%)	12 (7.8%)	15 (10.3%)	7 (12.5%)
Missing	37.3%	33.7%	43.7%	33.6%	32.7%
22M					
Anxiety	5 (1.1%)	1 (0.9%)	4 (2.6%)	3 (2.1%)	7 (12.5%)
Depression	19 (4.1%)	2 (1.8%)	8 (5.2%)	5 (3.4%)	4 (7.1%)
PEMH	25 (5.4%)	2 (1.8%)	9 (5.8%)	6 (4.1%)	8 (14.3%)
Missing	47.1%	42.3%	50.6%	46.7%	46.2%
24M					
Anxiety	11 (2.4%)	1 (0.9%)	4 (2.6%)	6 (4.1%)	0
Depression	19 (4.1%)	3 (2.7%)	3 (1.9%)	8 (5.5%)	5 (9.6%)
PEMH	23 (4.9%)	3 (2.7%)	5 (3.2%)	10 (6.8%)	5 (9.6%)
missing	55.5%	53.8%	63.8%	47.4%	48.1%

chronic-high-concern parents ($p = 0.007$) were significantly more likely to experience emotional mental health problems, especially depressive symptoms, between November 2021 and April 2022.

3.4. Quantitative indicators of future emotional mental health problems

Parents were more likely to experience emotional mental health problems if the household income was below £29500 (chi-square = 7.43, $p = 0.0064$) or they had difficulty accessing greenspace (chi-square = 8.22, $p = 0.0030$), especially in January/February 2022 ($P = 13.38$, $p = 0.0003$). Single parents were more likely to experience emotional mental health problems in November/December 2021 (chi-

square = 7.95, $p = 0.0048$), single status approached significant relationship with PEMH experienced in January/February ($p = 0.08$) and March/April 2022 ($p = 0.06$). Parents living in the North of England were more likely to experience emotional mental health problems in January/February 2022 (chi-square = 9.53, $p = 0.0492$), while parents caring for teens were more likely to experience emotional mental health problems in March/April 2022 (chi-square = 7.03, $p = 0.008$). Parental employment status, gender, age, number of children in household, urban location, gender child, vaccination status, and SARS-Cov-2 infection status did not affect PEMH.

3.5. Resilient factors decreasing parental concern

Our qualitative data revealed that in the face of COVID-19 pandemic challenges several different psychological adjustment processes unfolded. Below we describe coping/management strategies reported by the parents included in the mental wellbeing extension of the ImmunoCOVID-19 study to decrease parental concern.

3.5.1. Optimism

Many resilient parents approached the challenges coming their way during the pandemic with optimism (Table 3). When informed that their child was at no higher risk for SARS-CoV-2 infection than their peers and thus could unshield on August 1st 2020, parental worry increased a little but parents mentioned a need to return to a normal routine. The national lockdown during the first few months of 2021 was also taken in stride, as was the end of the British COVID-19 restrictions.

3.5.2. Informational support

A second strategy used by parents to decrease concern was to seek informational and structural support from child's clinical health care team, NHS medical helpline, school, friends, or medical disorder support groups.

(parent20SU023) 'my son is due back in school in September and I am quite anxious about this. I want him to wear a mask but he is not keen. I will be asking his consultant this week if he should go back in September, if it is worth the risk'

(parent20A024) 'I have contacted school as 2 cases have been confirmed, they have now allowed my son to leave his lesson 5 minutes early to attend his next lesson without bumping into people in busy corridor'

Occasionally conflicting advice was provided

(parent20A018) 'I feel the instructions which the cclg (Children's cancer and leukemia group) site give, are not in line with the government instructions. My son is at risk of lung problems due to a weakened immune system but cclg say I should be sending him to

school. I am no longer following the cclg's guidance regarding school and I am keeping my child at home.'

(parent21SP025) 'my son should have the vaccine. His consultant has written a letter of support but the GP is not keen to give it until he is 16 due to licensing.'

The parents experiencing higher levels of concern where sometimes disgruntled if the informational support given did not align with their beliefs.

(parent21SU026) 'Our child's doctors say they are "not allowed to" tell them to stay off school. Yet we are sure that a return to school would result in my children catching covid because there are no precautions and high community infection rates. So why are children being sent into unsafe schools and doctors are not speaking out for them??? They won't put in writing to support a child staying off school to stay safe from covid and they won't put in writing that it is safe for a child to be at school. Doesn't seem right that they want it both ways!'

In addition, seeking advice from friends and medical disorder support groups did not always have the desired effect.

(parent21SP027) 'I'm just concerned about the new strain of covid. And the impact of this on children. I'm part of a parents FB group we are all from Birmingham Children's Hospital and everyone is concerned that it may affect children more. It's a worrying time'

Occasionally parents were in need of informational support but were not sure where to turn to get this support

(parent21SP028 = 20A018 = 21W008) 'My child is extremely vulnerable, he has relapsed, going through chemotherapy and high dose chemotherapy soon and stem cell treatment. Yet we have received nothing to state he is extremely vulnerable, I cannot find where I request the letter and so I have to expose myself to selfish people not distancing or wearing masks in order to food shop and then I could be bringing home covid to my child.'

3.5.3. Reduction social isolation

Another coping strategy that was used to mitigate parental concern was to reduce social isolation.

(parent20SU004) 'This weekend we went away to a small hotel in Norfolk to escape London - most of our time was outside and at a beach. It is the first time we have left our neighbourhood since we went home to visit Family in December. It is the riskiest thing we have undertaken since the outbreak in March. we are worried that have ventured out, but felt it was important to hit the beach and get a break from the City.'

As indicated by parent20SU004, reducing social isolation only decreased parental concern if perceived psychological and financial benefits outweighed the perceived physical health consequences for the family.

(parent20A005) 'I am more worried about the effect of covid restrictions on my child's mental health than effect of virus on physical health. He is scared by the restrictions on freedom'

3.6. Risk factors increasing parental concern

The qualitative analysis also revealed several factors that seemed to increase concern of the parents included in the mental wellbeing extension of the ImmunoCOVID-19 study.

3.6.1. Perceived risk and impact SARS-Cov-2 infection

Perceived physical consequences were contingent on the multitude of factors (see Table 4). For instance, perceived physical consequences

Table 3
Resilient parents approaching COVID-19 challenges with optimism.

Parent ^a	Quote
20A001	'Returning to school this week so just a little anxious about that but sure it will be ok'
21W002	'If anything lockdowns and social distancing are making our experience better. I'd be worried if she got Covid I suspect but I'm so less worried about her getting anything else that on balance I'm really quite happy with the precautions. Now we aren't locked into excessive shielding in the house I don't really think that lockdown is too intrusive. We are quite calm and not really worried at all'
22SP003	'I feel its time that's it over now, no more restrictions, a recovery from mental health challenges and a return to life'

^a Parental ID: first 20 digits indicate the year (e.g. 20 for 2020, 21 for 2021 etc), letter indicates season (e.g. A = autumn, W = winter, SP = spring, SU = summer), last 3 digits randomly chosen.

Table 4
Perceived physical consequences of SARS-CoV-2 infection.

Parent ^a	SARS-Cov-2	Quote
20W006	<i>Exposure risk - prevalence</i>	'Our area is now in tier 4 which heightens our anxieties regarding our child catching covid'
21SP007		
21W008		
20A009	<i>Exposure risk-Ability adhere protective measures</i>	'I'm concerned about my child returning to school. He's takes Tacrolimus and Prednisone post liver transplant, but is also autistic, sensory seeking and has significant learning disabilities. He cannot understand social distancing or hygiene, puts everything in his mouth. As do a lot of his school peers. I don't think he's going to be safe there'
20SU010	<i>Exposure risk - Public's adherence to COVID-19 guidelines</i>	'Other people flouting the rules and meeting up in groups without the appropriate distancing or wearing masks. They're so selfish and stupid. It's because of those people that my daughter still cannot see her friends or family due to shielding. If people would just follow the advice the virus would be eliminated quicker.'
20A011		
20W012		
21SP013		'I am worried that people in general seem dismissive of those that are high risk"well you no longer have to shield" as if suddenly cos gov has declared end to shielding that it's safe.'
20W012		'I'm worried about people not being careful over the Christmas holidays. Everyone is having to reassess their plans, it's different this year - I just don't understand why some people think they are invincible and the rules don't apply. It just so irresponsible!'
21SP013		'Confirmed cases in my area are still high and a lot of people I have seen are acting like covid is over and mixing lots with no social distancing. When I have asked for people to clean their hands and wear mask they actually cough in the direction of my child. Causing a meltdown by parent as I worry for child ! I'm getting scared to let [child] out. I can't trust people to be thoughtful of others health.'
20A014	<i>Exposure risk – controlling environment</i>	'My child has stopped shielding, is returning to school- he is also changing from MMF to Azothiaprine .. I hope he doesn't flare or become more vulnerable to COVID (or anything else) .. I know it's letting go of control of his environment and I have to let him live his life in accordance with professional, trusted advice.'
20SP015	<i>Anticipated symptoms</i>	

Table 4 (continued)

Parent ^a	SARS-Cov-2	Quote
20SU016		'I'm worried about either of my children becoming so ill that they have to go to hospital and I can't go with them. I'm worried about them dying in hospital alone'
20SU017		'I'm worried that if he catches the virus he might die or be left with damaged lungs or some other life long condition if his body struggles to fight off the virus as it seems to affect everybody so differently. Not having enough knowledge about the virus and how it appears to affect people adds to my anxiety about how safe he will be from it moving forward and what the future might look like for him. Its all just a tad scary to be honest.'
20A018 (=21W008)		'Even if you get a mild version you can have long term renal and cognitive damage not to mention lung issues.'
21SP019		'I've watched my (CEV) child be extremely poorly lately, I don't want to go through that again with either child due to being forced to school in the middle of a pandemic.'
21SP020		'We are not sending him into school even though he is eligible for a place during this lockdown as I am an NHS worker due to our concerns about the new variant. We have really resumed shielding'
21A021	<i>Protective - vaccination</i>	'I am worried about catching COVID. I am single parent, looking after three children, twins and one of them has cerebral palsy, my eldest who has ERA, and my extremely vulnerable 90 year old mother, I am 52 and three of us also have mild asthma'
21SU022 (20SU010)		
21A021		
21A021		'I'm less worried than I was especially now he's had a COVID jab and his flu jab.'
21SU022 (20SU010)		'I'm still worried about my child as she is too young to be vaccinated. Even though the immediate people around her have been, taking her out into the wider community is scary as there is still a large proportion of the population not vaccinated. Reduced wearing of face masks and meeting people indoors is not something I feel comfortable with for my daughter. Until she can be vaccinated she'll continue to remain fairly isolated.'

^a Parental ID: first 2 digits indicate the year (e.g. 20 for 2020, 21 for 2021 etc), letter indicates season (e.g. A = autumn, W = winter, SP = spring, SU = summer), last 3 digits randomly chosen.

were dependent on exposure risk. (Local) prevalence of COVID cases, ability of family members to adhere to hygiene and personal protective measures, and public's adherence to COVID-19 guidelines all played a role in parental perception of exposure risk. The qualitative data seemed to suggest an increased perception of the public's lack of adherence with increased levels of parental concern.

Perceived physical health consequences of family members were also contingent on the anticipation of COVID-19 symptoms. With increasing levels of parental concern, a more severe SARS-CoV-2 impact was anticipated. Some parents admitted that an increase in concern came forth due to their decreased ability to control the vulnerable child's environment. Many parents believed the COVID vaccination to be a protective factor against these anticipated SARS-CoV-2 infection

consequences. Table 4 reveals that some of the perceived physical consequence factors changed throughout the COVID-19 pandemic.

3.6.2. Uncertainty

Every phase of the pandemic exposed the parents caring for an immunosuppressed child to new uncertainties.

(parent20A029) ‘Uncertainty is the main worry, but I suspect that is true for everyone. I am worried about what I should and shouldn’t be doing. Should we still be isolating or can we carefully continue as “normal.”’

Parents were often confused about what their immunosuppressed child was allowed or safe to do. A lot of questions surfaced around the availability and safety of the COVID vaccine for vulnerable children.

3.6.3. Social media

Increased use of social media often increased parental concern.

(parent20A030) ‘Worried about long term effects of virus on younger generation - reading some articles in newspapers (shouldn’t google!)’

(parent21SU026) ‘Is it true that 900 children with covid have been admitted to hospital this month? (twitter)’

... and especially in the domain of vaccination, parents who turned to social media to seek knowledge often experienced increased concern

(parent21A031) ‘It disgusts and angers me that even in light of the Joint Committee of Vaccination and Immunization’ advice to NOT vaccinate 12–15 year old that the Government are going to do it anyway! It’s utter insanity, with article papers finding the 64% of young males developing myocarditis, and others suffering Multiple Inflammatory Organ Disease. For 18 months we were told that children were unaffected by covid and not to worry! Now they’ve finished vaccinating all the upper cohorts, they decide that the children are at risk, despite proof they’re not’

3.6.4. Government support

Most parents were disappointed by the support and advice given by the British government. Parental comments ranged from the following in the beginning of the pandemic ...

(parent20A032 = 21SP027) ‘I’m worried about the effects on my son’s mental health. It seems as though children aren’t being severely affected by Coronavirus yet there has been no updates from the government about this. My son’s life was on hold due to ill health for many years. Now that he has his life back it would be nice if he could enjoy it. Either an update from the Gov or NHS would be appreciated on these uncertain times.’

... to this comment when transitioning from pandemic to epidemic.

(parent22SP033) ‘I’m quite worried due to the latest news regarding the English government planning to stop all covid rules/regulations, particularly regarding testing, tracing and isolation. This leaves CEV people completely vulnerable with no way of knowing who has the virus or how to protect themselves’

Some of the government COVID guidelines went against parental instincts to protect their children.

(parent20A034) ‘Being back at school and mixing with others is a concern. I don’t want my child in school but been told I would get fined if she didn’t attend’

3.6.5. Household

Family circumstances also impacted parental response to the challenges of the COVID-19 pandemic. Quite often the household shielded

more vulnerable individuals than just the immunosuppressed child or the parent was a keyworker and concerned about bringing SARS-CoV-2 infection home from work. Occasionally the child’s level of mental distress caused parental concern.

(parent21A035) ‘from an anxiety perspective, my son’s school has had a Covid outbreak in the past week - my son missed pretty much a whole year due to shielding/transplant last summer/lockdowns. He’s 7 and cried going to school on Monday about siblings from Covid positive houses being able to attend school, as some are in his class. I think he feels like he’s gone from being protected, to now not being protected at all, as an immunosuppressed child - pretty heartbreaking to see’

4. Discussion

The findings of this prospective national study indicate that the psychological response of the parents included in the ImmunoCOVID-19 study to the adversities experienced while caring for their immunosuppressed child during the first 2 years of the COVID-19 pandemic followed a resilient, recovery, or enduring high level of concern pathway. The delayed concern pathway was not observed, but a decade of resilience theory studies has only rarely revealed individuals who responded to adversity following a delayed response pathway (Galatzer-Levy et al., 2018).

Using a mixed method approach our qualitative findings include a rich description of the previously quantitatively identified association between psychological response trajectories and risk/resilience factors such as individual differences (optimism support, over indulgence social media, social isolation), family context (household income), and community characteristics (level exposure to COVID-19 in north of England). New to the community characteristics identified in adversity research (Chen and Bonanno, 2020) was the mitigating effect of access to greenspace. Pre-COVID-19 population-based longitudinal studies (Feng and Astell-Burt, 2018) and cross-sectional COVID-19 studies (Larson et al., 2022) have shown the importance of greenspace access to the experience of psychological distress, but never theorized this factor as a resource mitigating the impact of adversity. The prolonged period of adversity with frequent periods of social isolation experienced during the COVID-19 pandemic made access to greenspace one of the protective factors associated with resilience to the psychological impact of the COVID-19 pandemic for parents caring for an immunosuppressed child.

In agreement with other COVID-19 research studies (Brooks et al., 2020) our findings demonstrated that lack of reliable information and guidance has contributed to shaping parents’ degree of emotional mental wellbeing and concern. The media’s coverage of the COVID-19 pandemic was high, but framing of the pandemic, focusing mostly on individual human interest, attribution of responsibility, economic consequences, and the language used in the coverage reflecting pessimistic and alarmist tones (Ogbodo et al., 2020) inspired fear instead of promoting calm. Mistrust in British government COVID guidance further enhanced this fear (Freeman et al., 2022), leading in some parents caring for an immunosuppressed child to reject vaccination and question government COVID guidance for vulnerable individuals. Could medical condition specific information on SARS-CoV-2 infection risk, expected severity of illness, treatment, and vaccination efficacy and safety from a reputable medical authoritative organization have assuaged parental concern?

Important for intervention purposes was the finding that heterogeneous subtypes of parental concern were differentially associated with the experience of emotional mental health of British parents caring for an immunosuppressed child during the COVID-19 pandemic. Similar findings were found by Bonanno et al. (2008) when they explored individual response to the 2003 SARS-Cov-1 outbreak in Hong Kong. The association could have been more pronounced had it not been for the psychologically-induced survey drop-out, not only found in the

ImmunoCOVID-19 study but also reported by research teams collecting data for other cohort studies (Wolke et al., 2009).

4.1. Strength and limitation

Most British COVID-19 cohort studies focused on the general population instead of marginalized populations. Although the sample used in this study is not a probability sample, we did focus on individuals more vulnerable to the COVID-19 pandemic. The form of convenience sampling used in this study was employed by the majority of COVID-19 studies to quickly deploy data collection within a brief time frame during the initial phase of the pandemic, despite awareness of the possibility of selection bias. Selection bias in this study was not only caused by the sampling frame used, but also by self-selection of the families volunteering to participate in the ImmunoCOVID-19 study, and the attrition rate. Although these forms of selection bias impact the generalizability of the results, the collection of weekly data from a vulnerable population with diverse demographic backgrounds provided a unique opportunity to examine how things have changed over time throughout the pandemic, and, crucially, for whom.

As no pre-pandemic data is available on the participants included in the ImmunoCOVID-19 study, we can only conclude that our data showed an association between the experience of parental concern and emotional mental health problems. It cannot be ascertained if these emotional mental health problems were already present before the COVID-19 pandemic and therefore caused higher levels of parental concern during the COVID-19 pandemic or if the parental concern experienced during the COVID-19 pandemic increased parental likelihood of experiencing emotional mental problems. More in-depth research should be undertaken to fully understand this association between parental concern and parental experience of emotional mental health problems.

5. Conclusion

The findings of this prospective longitudinal study created a window into the psychological wellbeing of British parents caring for a vulnerable child during the COVID-19 pandemic. Although most parents slowly recovered from psychological impact of the adversities experienced during the COVID-19 pandemic, the findings suggest a need for routine psychological screening of families with immunosuppressed children to better identify those vulnerable to and not recovering from psychological concern and distress and to better inform targeted family intervention programmes. The resilient and risk factors mentioned by parents caring for an immunosuppressed child during the COVID-19 pandemic indicate a need to widen parental coping tool options to improve management and navigation of unpredictable circumstances, opposing demands, and/or unexpected constraints.

Credit author statements

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Declaration of competing interest

The authors declare no conflict of interest.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jpsychires.2023.03.021>.

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