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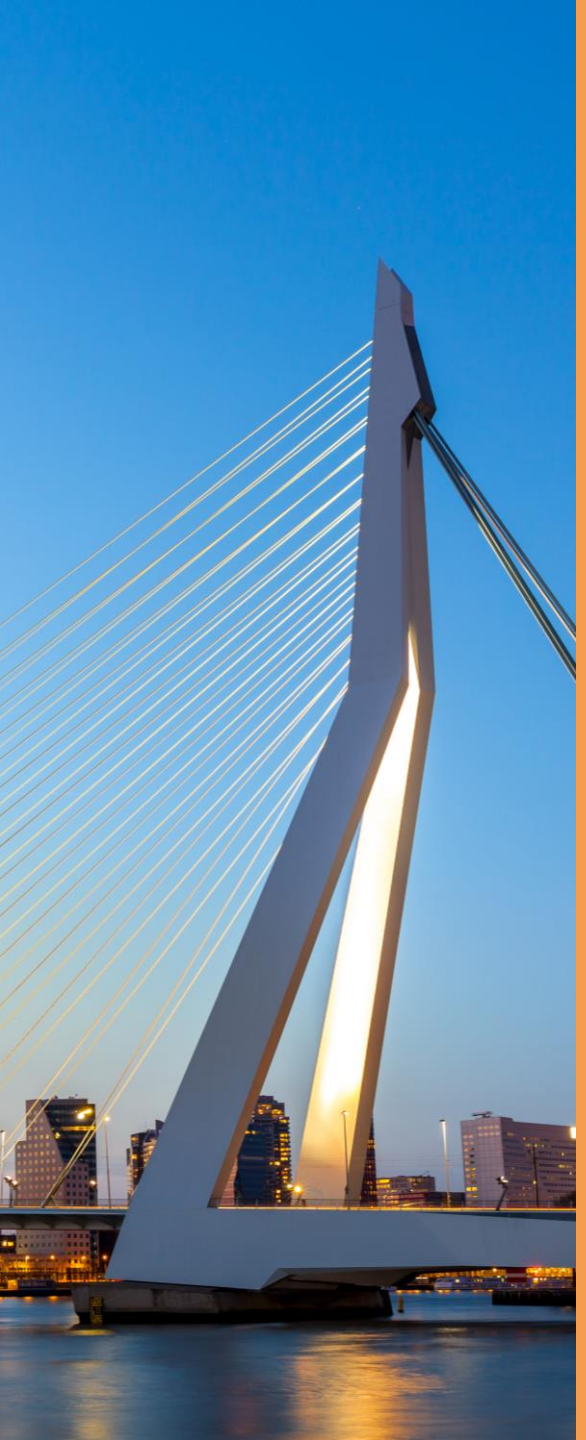

Impact of COVID-19 pandemic on clinical care of patients and Psychological health of affected families with Chronic Granulomatous Disease: an observational study from North India

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Session: *Young PID investigators: poster winners' session*

Date: 10 November 2023

Background

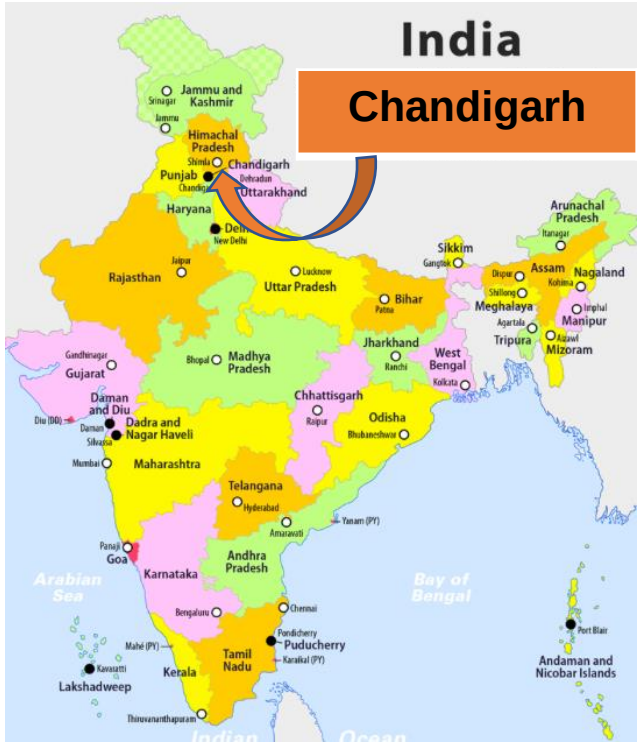
- Since its emergence in December 2019, the Coronavirus disease-2019 (COVID-19) has **affected clinical care** of many chronic illnesses including children with chronic granulomatous disease (CGD)

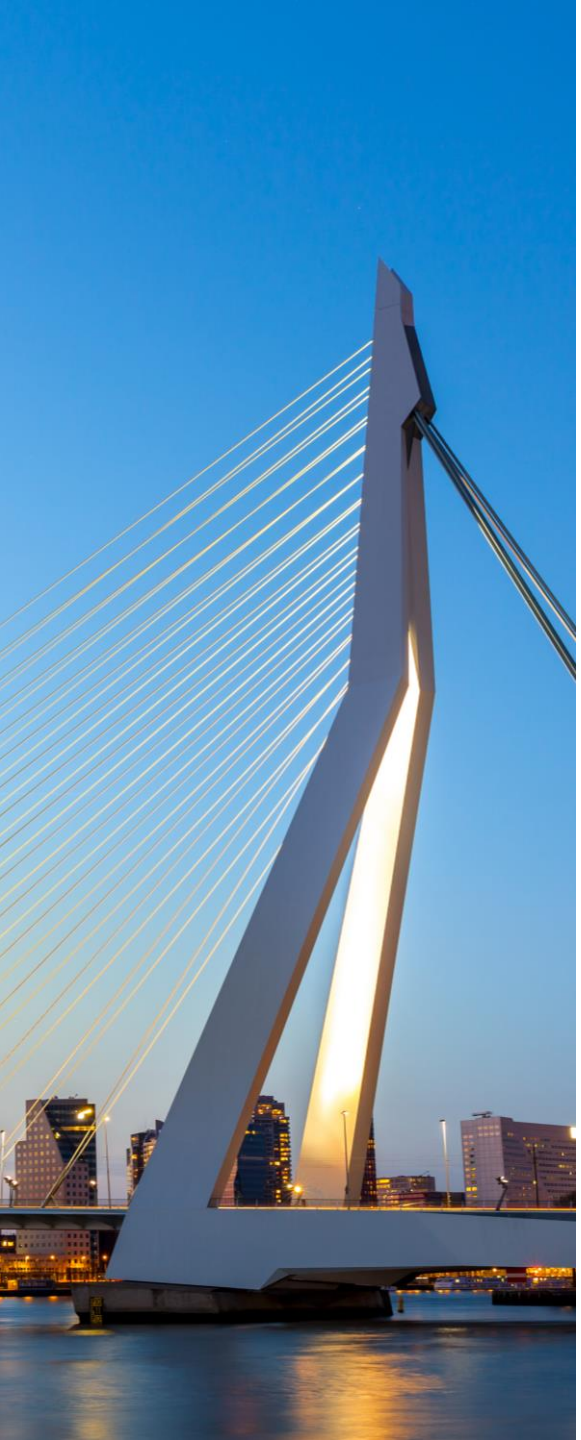
- **Nation-wide lockdowns** have adversely affected the **psychological milieu** of **parents/caregivers** who are looking after children with chronic diseases such as CGD

- There is **paucity of literature** on clinical care and psychological profile in parents/caregivers of CGD, in the context of COVID-19

Aims and Objectives

- To report the **clinical manifestations** of COVID-19 infection and its resultant complications in our cohort of **CGD** from **North India**
- To describe the **psychological** status of **<u>parents/caregivers</u>** of children with CGD during COVID-19 pandemic, from the perspective of a developing country





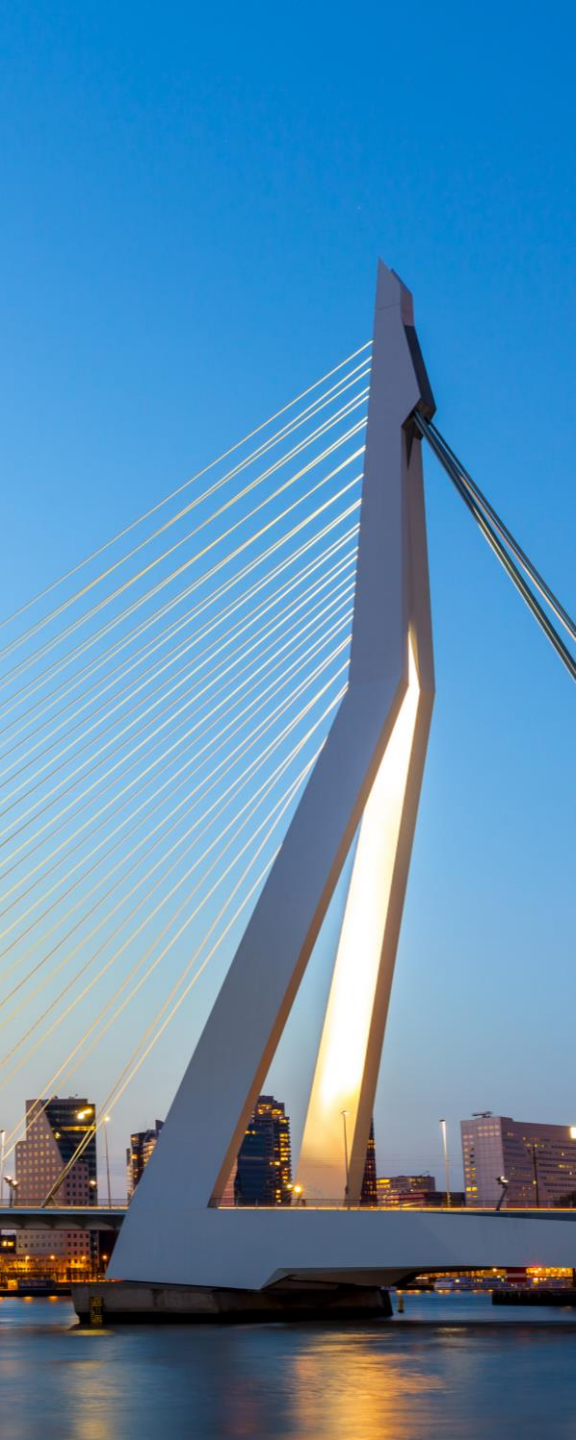
Methodology

- **Study design:** Cross-sectional observational study

- **Study setting:** Paediatric Allergy Immunology Unit, Department of Paediatrics, Advanced Paediatrics Centre, Post Graduate Institute of Medical Education and Research, Chandigarh

- **Inclusion criteria:**

❖ Children with CGD (n=101) who had infections or complications due to COVID-19



Methodology

- **Psychological scales:**

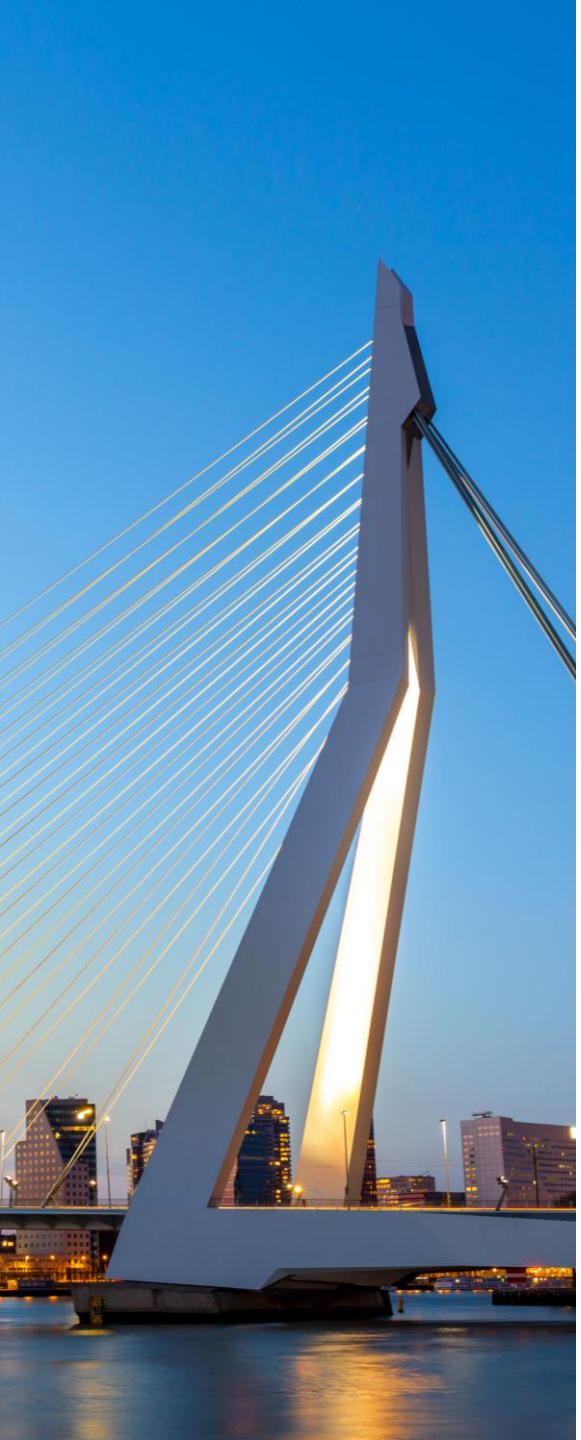
❖ Impact of Event Scale (**IES-R**)

❖ Depression, Anxiety and Stress Scale (**DASS 21**)

❖ Fear of COVID-19 Scale (**FCV 19S**)

❖ Preventive COVID-19 Behavior Scale (**PCV 19BS**)

COVID-19 Psychological wellbeing questionnaire



Methodology

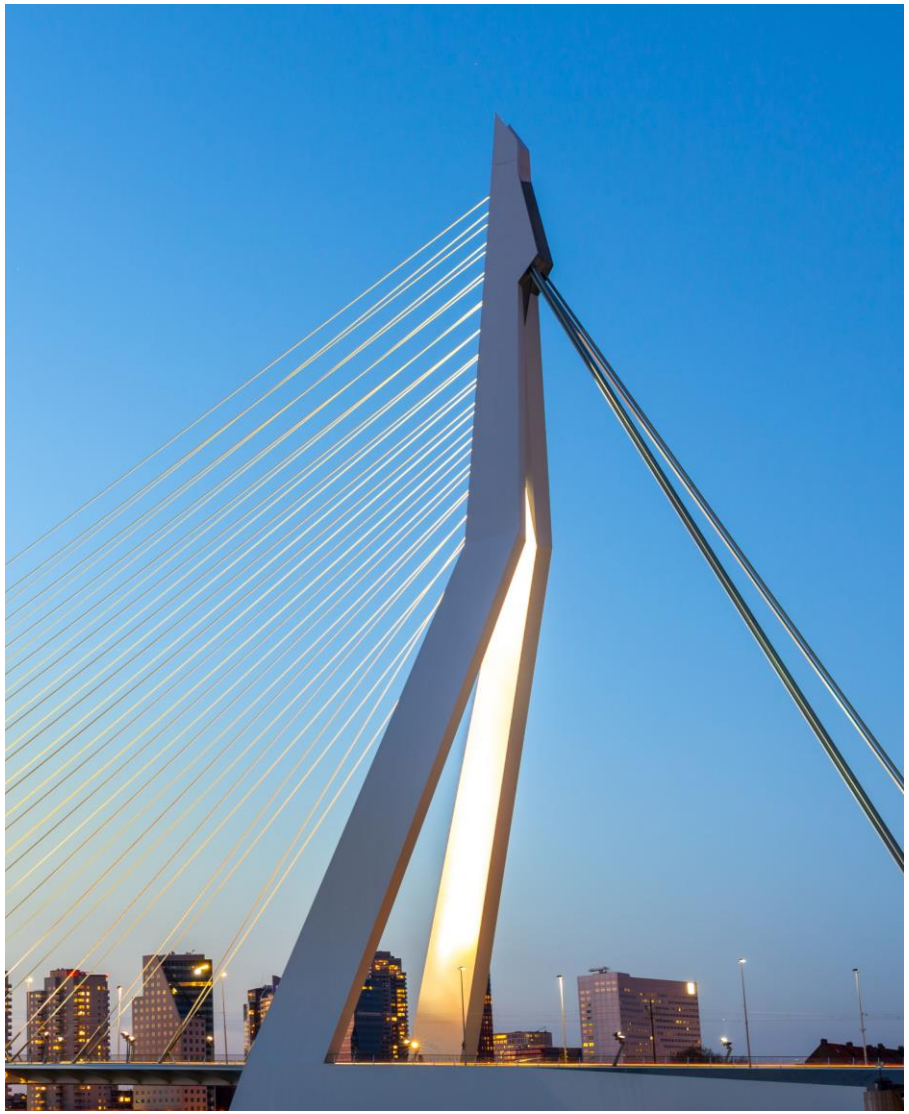
- Only those parents/caregivers who gave **informed consent** and **understood/answered** all sections of the questionnaire were recruited in the present study

- Parents/caregivers were assessed **personally** or **telephonically** by a trained psychologist or senior resident (post-doctoral fellow) on study measures

Responses of parents/caregivers of CGD (N=21)

Responses of parents/caregivers of healthy children (N=21)

Results



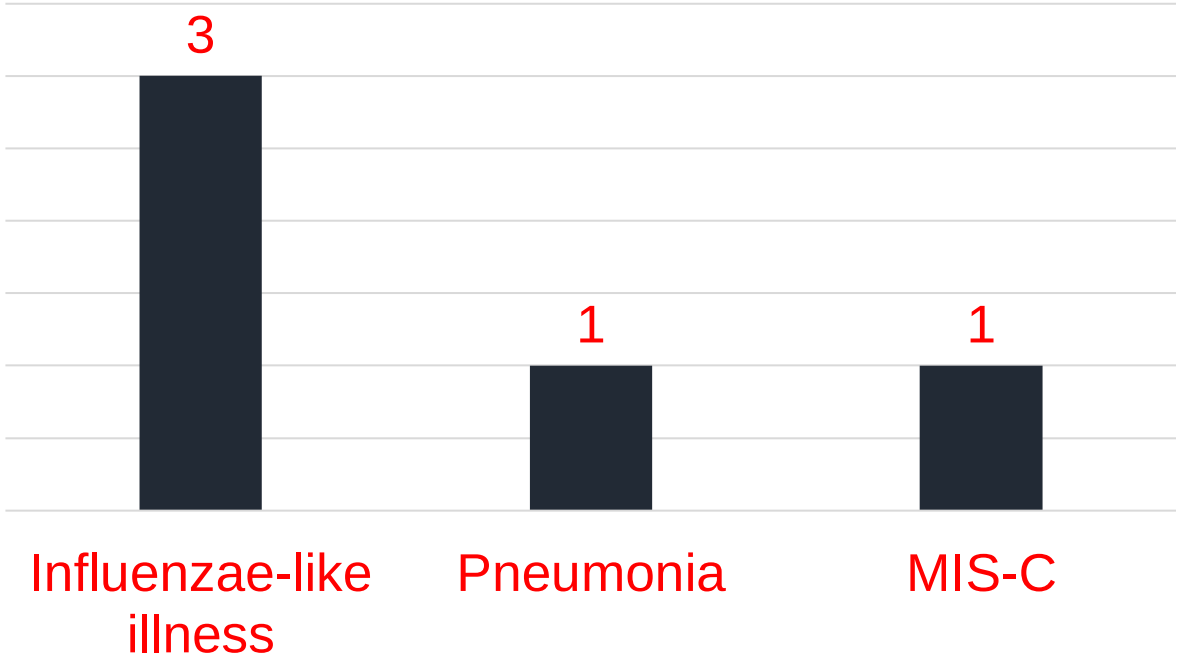


Fig: Clinical manifestations of COVID-19 infection in our cohort of children with CGD

***MIS-C:** Multisystem inflammatory syndrome in children

Results

Patients	Age (years)	Genetic defect	Clinical features	Management	Outcome
Case 1	15	*NCF1*	Mild fever, influenzae-like illness	Conservative	Asymptomatic after 5 days
Case 2	18	*NCF1*	Cough, nasal discharge, anosmia	Conservative	Asymptomatic after 4 days
Case 3	15	*NCF1*	Cough, nasal discharge, anosmia	Conservative	Asymptomatic after 4 days
Case 4	4	*CYBB*	Fever, cough, cervical lymphadenitis (*S. aureus)*	Conservative	Asymptomatic after 14 days
Case 5	10	*NCF2*	MIS-C	Intravenous methylprednisolone (30 mg/kg/day for 3 days followed by oral taper)	Became afebrile after 24 hours of initiation of steroid

Results

Demographic Parameters		Parents/caregivers of CGD (n=21) Group I	Parents/caregivers of healthy children (n=21) Group II
Age (in years) Range		41.76 ± 7.90 (28-60 years)	41.76 ± 7.90 (28-60 years)
Gender	Male	28 (66.7%)	28 (66.7%)
	Female	14 (33.3%)	14 (33.3%)
Education:	Intermediate	13 (61.9%)	10 (47.6%)
	Graduate/Postgraduate/Doctorate	8 (38.1%)	11 (52.4%)
Occupation	Elementary Occupation/House Makers	9 (42.9%)	5 (23.8%)
	Skilled/Semiskilled/Agriculture/ Shop	9 (42.9%)	4 (19.0%)
	Clerical/Ministerial staff	2 (9.4%)	5 (23.8%)
	Associate Professional/Professional	1 (4.8%)	7 (33.4%)
Socio-economic Status (SES)	Upper Lower	6 (28.6%)	4 (19.0%)
	Lower Middle	9 (42.9%)	1 (4.8%)
	Upper Middle	6 (28.6%)	12 (57.1%)
	Upper	0 (0%)	4 (19.0%)
Family Type	Nuclear	10 (47.6%)	12 (57.1%)
	Joint	11 (52.4%)	9 (42.9%)
Locality	Urban	11 (52.4%)	16 (76.2%)
	Rural	10 (47.6%)	5 (23.8%)

Results

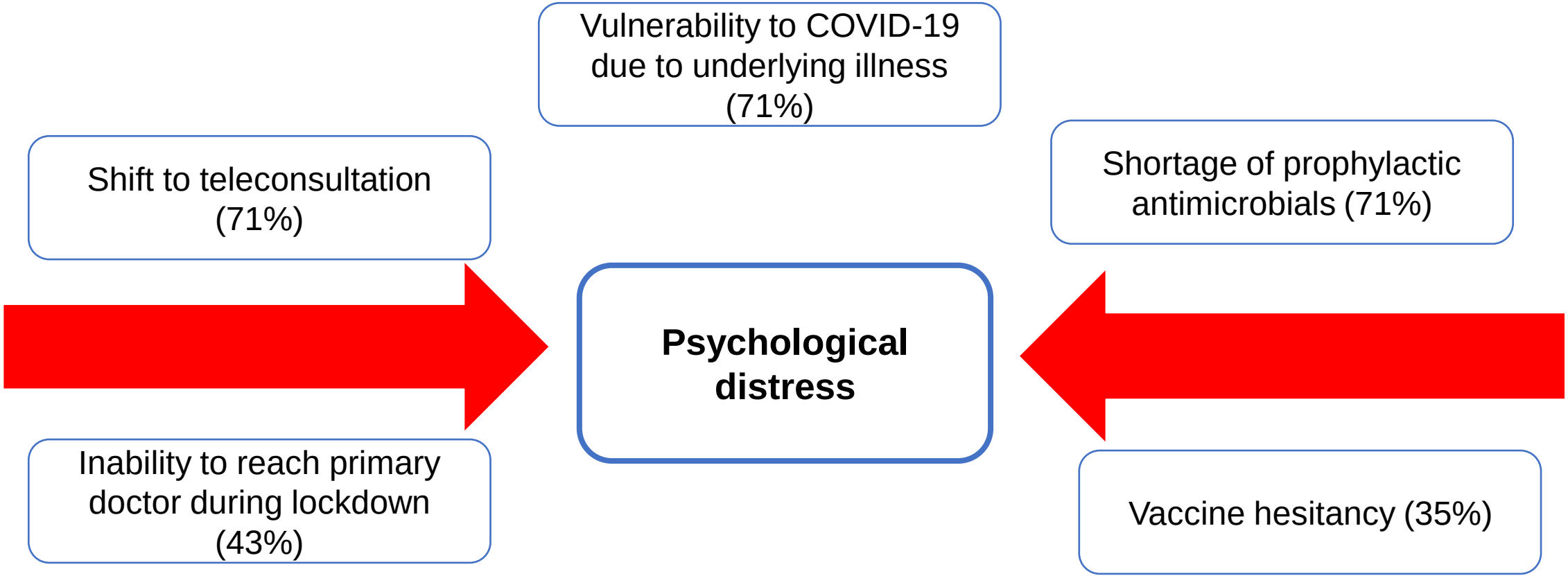
Variables	Group I (n=21) Median (IQR)	Group II (n=21) Median (IQR)	K Wallis	P value
The Impact of Event Scale (IES-R)				
Intrusion	**9.00** (6.00)	3.00 (6.00)	15.129	0.000
Avoidance	**12.00** (3.00)	4.00 (9.00)	17.007	0.000
Hyper arousal	**7.00** (6.00)	1.00 (4.50)	15.606	0.000
Total IES	**26.00** (9.50)	10.00 (17.00)	18.878	0.000
Depression, Anxiety and Stress Scale (DASS 21)				
Stress	**12.00** (10.50)	8.00 (5.00)	1.674	0.196
Anxiety	**8.00** (5.00)	4.00 (6.00)	5.565	0.018
Depression	**8.00** (6.00)	6.00 (4.00)	5.009	0.025
Fear of COVID 19 Scale (FCV 19S)				
Emotional Fear Reaction	**11.00** (9.00)	7.00 (3.50)	2.157	0.142
Expressional Fear	**7.00** (3.00)	4.00 (2.50)	1.911	0.000
Total FCV	**17.00** (7.50)	12 (3.50)	11.203	0.001
Preventive COVID 19 Behavior Scale (PCV19BS)				
Preventive Behavior	**41.00** (6.00)	39.00 (3.50)	5.356	0.021

Association between clinical and socio-demographic variables

	IES I	IES II	IES III	IEC Total	STR	DEP	FCV II	PCV
Education	--	-.350*	-.437**	-.360*	-.357*	--	--	--
Occupation	-.436**	--	-.481**	-.406**	--	-.409**	-.314*	-.215
Income	-.537**	-.463**	-.611**	-.568**	-.537**	-.505**	-.401**	-.322*
SES	-.502**	-.370*	-.584**	-.514**	-.434**	-.418**	-.351*	-.295

- Significant at 0.005 ** Significant at 0.001
- Impact of Event Scale=IES I: Intrusion; IES II: Avoidance; IES III: Hyper arousal; Depression, Anxiety, Stress Scale (DASS)=STR: Stress, DEP: Depression; Fear of COVID-19 (FCV)= FCV II: Expressional Fear; Preventive Behavior Scale=PCV

Summary of results



Summary of results

↑↑ FCV 19S

Psychological distress

↑↑ PCV 19BS

- **Frequent handwashing**
- **Social distancing**
- **Wearing masks**

71% reported less infections during the pandemic

Literature review

Author, year, country	Total number of patients with IEIs who contracted COVID-19	Total number of patients with CGD who contracted COVID-19	Impact of COVID-19
Meyts et al, 2021, Europe, South America, USA, Australia	**94**	**4**	About 1/3rd of patients with IEIs had a predominantly **mild clinical course with COVID- 19 infection**
Goudoris et al, 2021, Brazil	**121**	**4**	The outcome of patients with IEIs who had contracted COVID-19 was **mild in a majority** of cases
Carter-Timofte et al, 2020, Denmark	**NA**	**NA**	IEIs that have **defective production of type I IFNs** were more likely to have **severe COVID-19 infection**
Yazidi et al, 2021, Oman	**140**	**NA**	No IEI patient had been admitted to hospital due to COVID-19 related illness
Marcus et al, 2021, Israel	**20**	**2**	Most IEI patients had a **mild course** and none of them required hospital admission
Delavari et al, 2021, Iran, Sweden	**19**	**2**	Patients with **combined immunodeficiencies** and **immune dysregulation** had higher mortality rate as compared to general population

Literature review

Author, country, year	Total number of CGD patients and/or families	Psychosocial scales/ outcome measures used	Remarks
Cole et al, UK, 2013	§	PedsQL SDQ	**Patients** and **caregivers/parents** of children with CGD have **lower quality of life** and poor emotional health, however, those who undergo HSCT have comparable emotional health to healthy controls
Battersby et al, UK, 2019	75	SF-36 V2 HADS	All XL-CGD carriers had **reduced quality of life** Amongst XL-CGD carriers, 26/61 and 5/61 reported moderate-to-severe **anxiety** and **depression** respectively
Pulvirenti et al, Italy, 2019	47	PedsQL SDQ SF-12	Children with CGD reported more problems in **social/school areas, peer relationship, and conduct/emotional** problems as compared to controls No significant difference was noted between patients who underwent HSCT versus those who did not

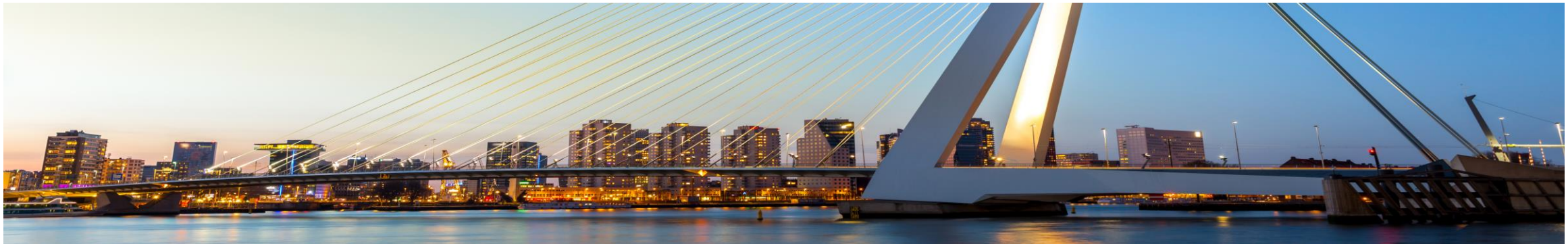
PedsQL: Pediatric Quality of Life Inventory; SDQ: Strengths and Difficulties questionnaire; SF-36 V2: Medical Outcomes Study Short Form 36 version 2; HADS: Hospital Anxiety and Depression Scale;; SF-12: 12-item Short Form health survey

§Forty-seven and 42 parents completed PedsQL and SDQ questionnaires respectively, and 35 children completed self-report PedsQL questionnaires

*X-linked carriers of CGD: 75

Conclusion

- Children with **CGD** have had predominantly **mild infection** with **COVID-19**
- Scores for **stress**, **anxiety**, and **distress** were significantly elevated in **parents/caregivers**
- Timely recognition of the **psychosocial** concerns is essential for identifying **personalized psychological support**
- Future studies should evaluate psychological **interventions** such as psychoeducation, cognitive behavioural therapy, counselling, and family therapy with a larger sample size in patients with CGD and their caregivers/ parents



Acknowledgment

Consultants, DM Fellows and PhD students of Paediatric Allergy Immunology Unit, PGIMER, Chandigarh

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