

Impact of COVID-19 pandemic on parents of children with CF: an observational study

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COVID-19: Impact on people with cystic fibrosis (pwCF) and their caregivers, already at increased risk to develop symptoms of stress, depression and anxiety ^{1,2}

- Disruption in daily life for individuals and families
- Loss of normal routines, reduction of activities and social isolation
- Psychological and psycho-social implications ³⁻⁵

distress, depression, anxiety, anger and irritability, adjustment disorders

¹Quittner et al., Thorax 2014

²Graziano et al., Respiratory Medicine 2020

³Havermans et al., Journal of CF 2020

⁴Ciprandi et al., Journal of CF 2020

⁵Pinar Senkalfa et al, Pediatr Pulmonol. 2020

TO ASSESS STRESS AND MENTAL HEALTH IN A GROUP OF ITALIAN PARENTS OF CHILDREN WITH CF, ONE YEAR AFTER THE COVID PANDEMIC

PARTICIPANTS

20 parents (F/M=18/2) of children aging 4-12 years ($M/SD = 8/3$)

Enrollment between February-April 2021

10% (N=2) affected by COVID-19 more than 2 months before the evaluation

MEASURES

Patients Health Questionnaire-9 (PHQ-9)



Generalized Anxiety Disorder-7 (GAD-7)

COVID-19 Exposure and Family Impact Scale (CEFIS)*

**Italian translation of the measure was performed according to FDA and EMA guidelines*

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www.healthcaretoolbox-org/covid19



FORWARD-TRANSLATION & BACK-TRANSLATION

Two native Italian speakers, experts in CF, translated the CEFIS from English into Italian.



An e-mail communication was conducted to discuss and resolve discrepancies to produce the “consensus forward” Italian version, focusing on cultural equivalence and specific terms.



The consensus measure was back-translated into English by an Italian speakers with strong English skills, followed by an e-mail communication to ensure the instructions, items, and rating scales conveyed original meaning



It was administered to **5 individuals** using cognitive probes to assess clarity of items, rating scales, and comprehensiveness.



COVID-19 Exposure and Family Impact Scale

(CEFIS; Kazak et al., 2020)

PART 1 – EXPOSURE SCALE

- 25 items - “Yes/No/Not applicable” responses
- experience with potentially traumatic events related to pandemic

PART 2 – IMPACT SCALE

- 9 items 4-point Likert Scale “made it a lot better – made it a lot worse”
- How pandemic affected everyday life

PART 3 – STRESS SCALE

- 2 items 10-point Likert Scale “no distress - extreme distress”
- Individual and family levels of stress

COVID-19 Exposure and Family Impact Scale

(CEFIS; Kazak et al., 2020)

PART 1 – EXPOSURE SCALE

- We had a stay at home order
- Our school/childcare closed
- Difficulty getting healthcare
- Someone exposed to COVID-19
- Family income decreased

Yes/No
Not Applicable

COVID-19 Exposure and Family Impact Scale

(CEFIS; Kazak et al., 2020)

PART 2 – IMPACT SCALE

“COVID-19 may have many impacts on you and your family life. In general, how has the COVID-19 pandemic affected each of the following...”

- Parenting
- Ability to care for your child with [add illness/condition]
- Your emotional wellbeing – anxiety
- Your emotional wellbeing – mood

1	2	3	4	
Made it a lot better	Made it a little better	Made it a little worse	Made it a lot worse	Not Applicable

COVID-19 Exposure and Family Impact Scale

(CEFIS; Kazak et al., 2020)

PART 3 – DISTRESS LEVELS

“Overall, how much distress have you experienced related to COVID-19?”

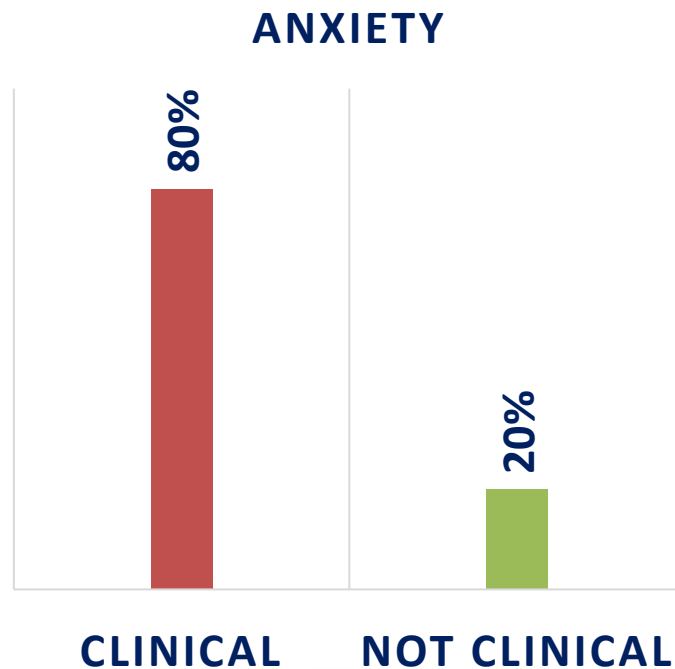
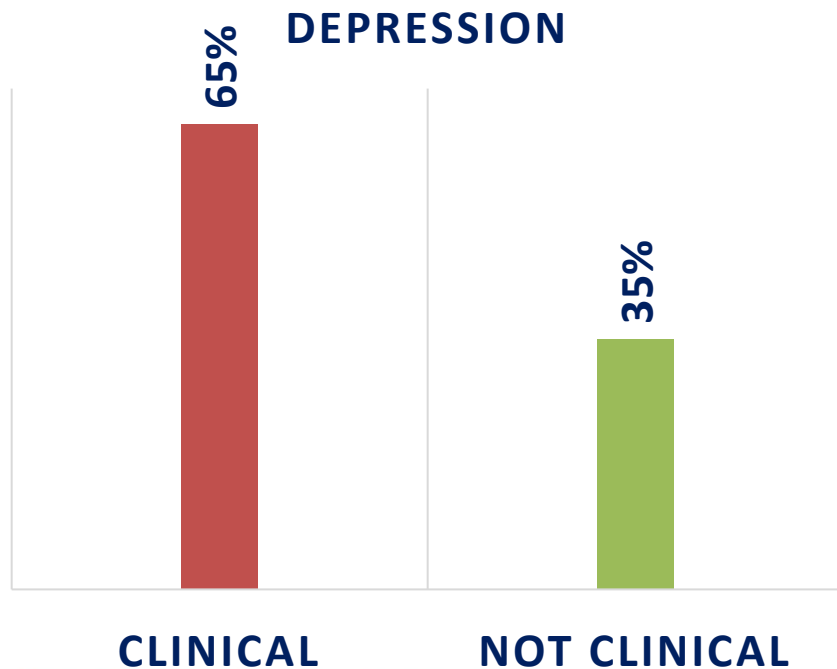
“In general, across all your children, how much distress have your children experienced related to COVID-19?”

- 10-point Likert scale
- Individual and family level

1	2	3	4	5	6	7	8	9	10
No Distress									Extreme Distress

RESULTS

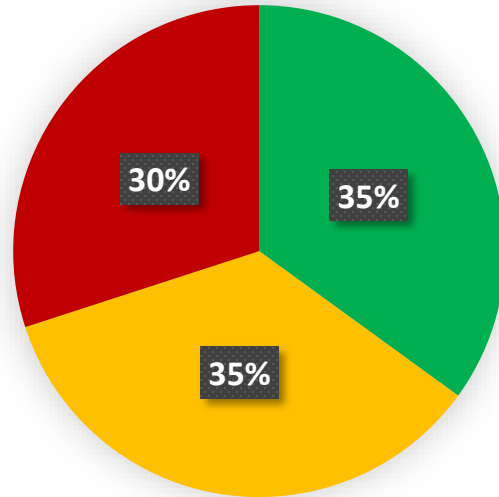
RESPONDENTS SCORING ABOVE THE CLINICAL CUT-OFF



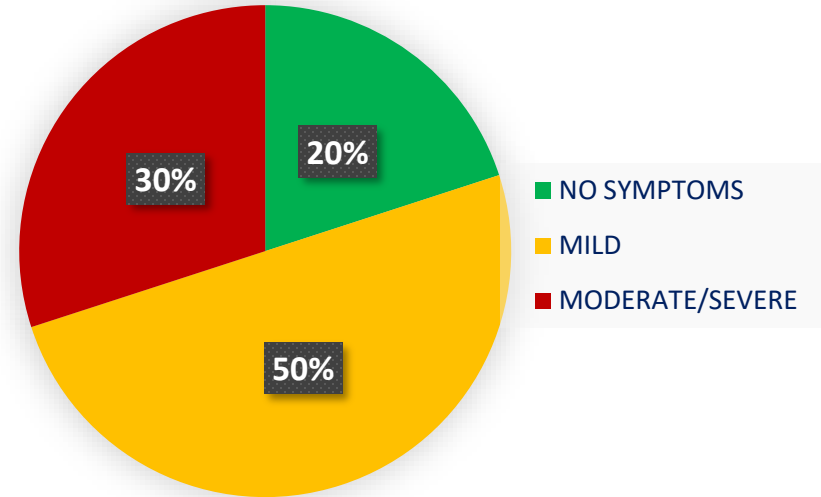
RESULTS

CLINICAL RANGES

DEPRESSION



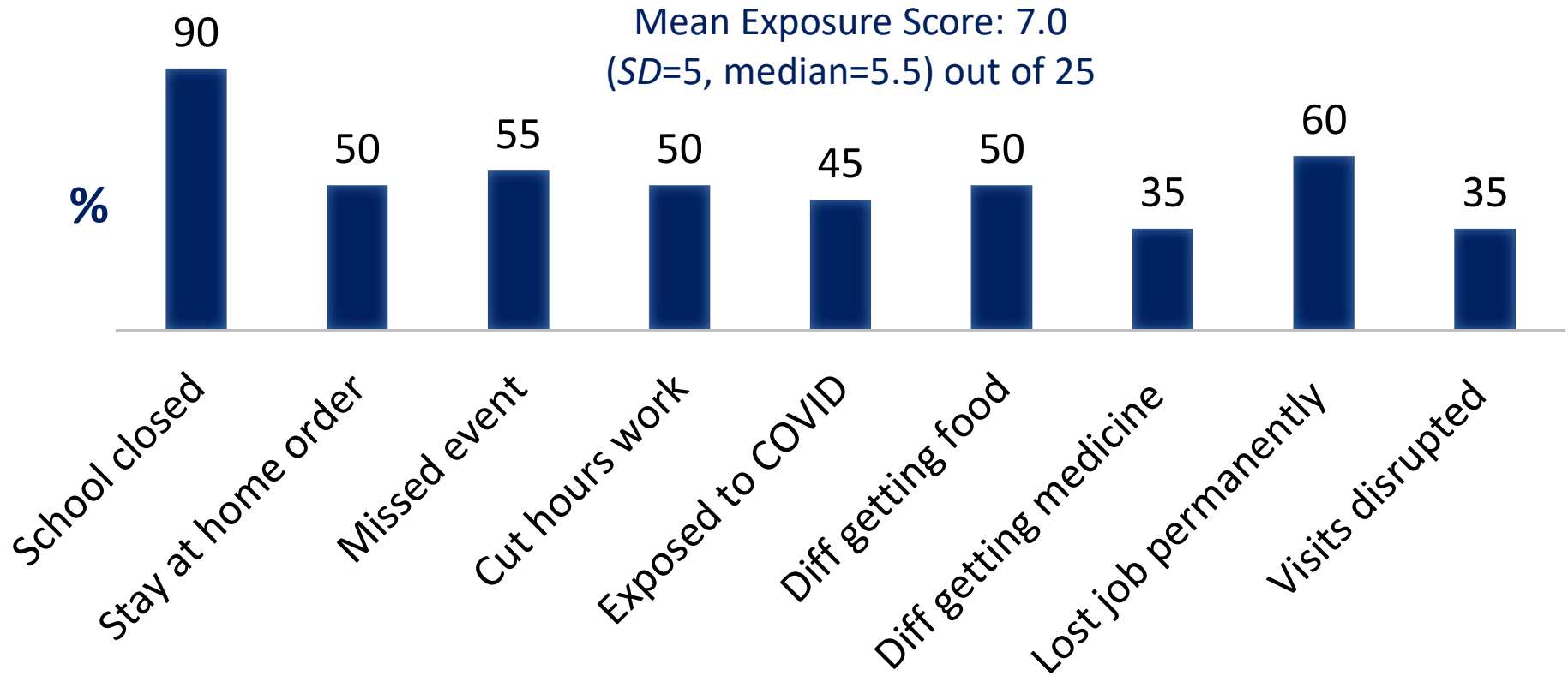
ANXIETY



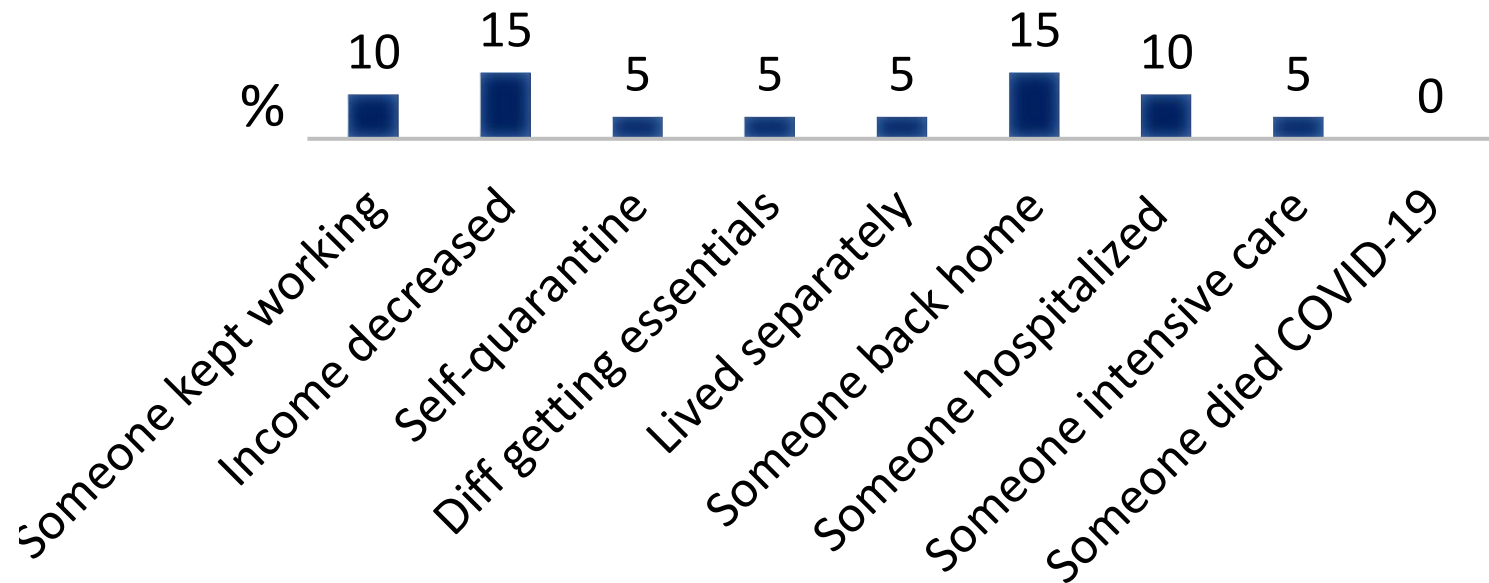
- NO SYMPTOMS
- MILD
- MODERATE/SEVERE



MOST FREQUENTLY **ENDORSED ITEMS – CEFIS EXPOSURE SCALE**

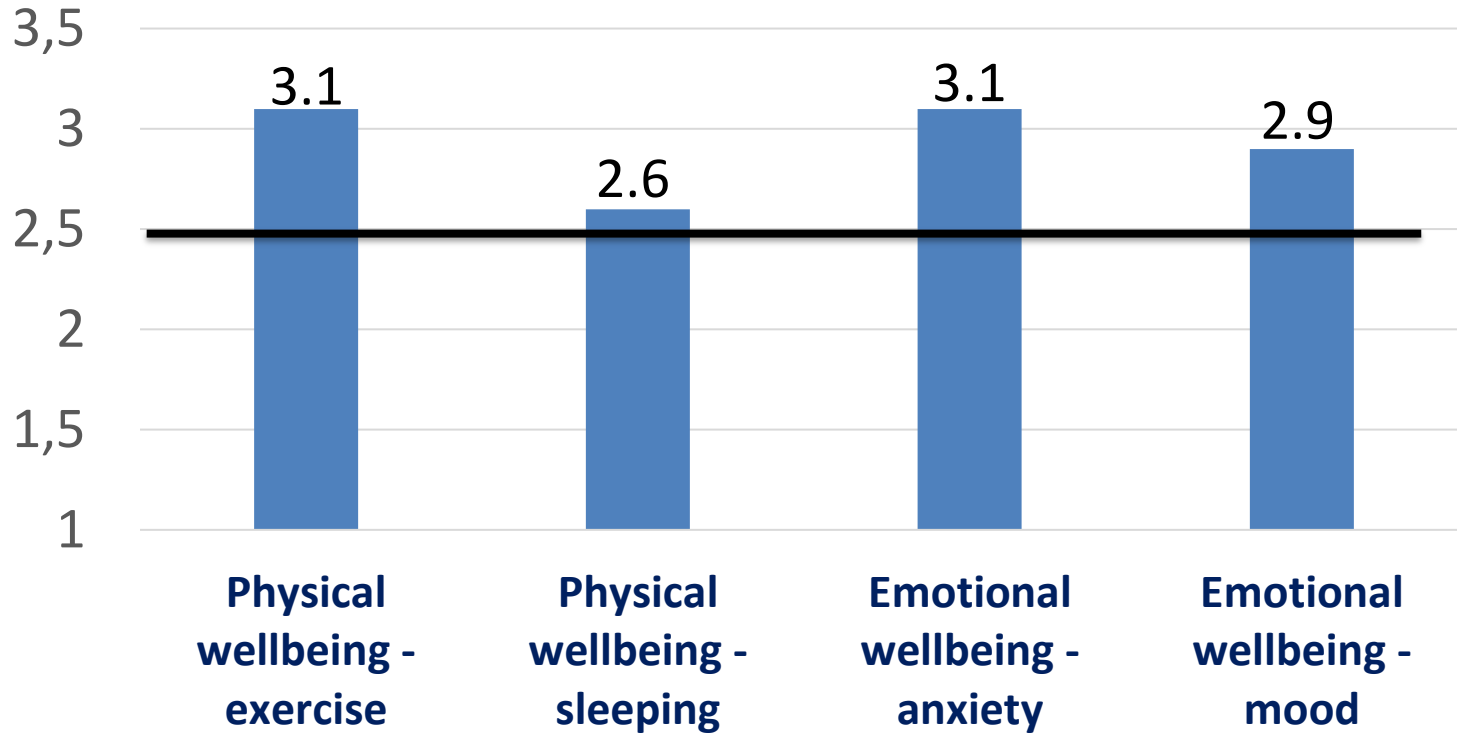


LESS FREQUENTLY ENDORSED ITEMS – CEFIS EXPOSURE SCALE



CEFIS – IMPACT SCALE

(mean score 2,5 = negative impact)



LEVEL OF DISTRESS

Average
distress
rating: 7.1
(*SD*=1.5)

FAMILY LEVEL

Average
distress
rating: 7.2
(*SD*=1.6)

INDIVIDUAL LEVEL



DISCUSSION - CONCLUSION

- Parents psychological wellbeing of children with CF appears still vulnerable, with elevated levels of stress and high anxiety and depression
- Adverse effects of pandemic added to an already at-risk condition, represented by the emotional fatigue associated to the adaptation to the diagnosis process
- To measure and to evaluate how families continue to be impacted by COVID-19 could be of great value, facilitating delivery of high-quality healthcare

