

## **A cognitive intervention program for reduction of stress in parents of children with intellectual and multiple disabilities: the effect on behavior problems and program adaptation through COVID-19 pandemic**

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### **Abstract**

Much evidence suggests that parents of children with special needs have elevated levels of stress when confronting with children's problems. This article presents a validation of a multimodal cognitive program for reducing parental stress in parents and children behavior problems of children with special needs that can be applied during COVID-19 pandemic. A study including 63 parents of children with special needs shows that the program is effective both in reducing parental stress and children's behavior problems reported by parents. Recommendations for the online use of the program and adaptations to the COVID-19 pandemic characteristics are made.

**Keywords:** COVID-19 pandemic, stress, cognitive therapy, parents, disabilities, behavior problems

The COVID-19 pandemic and the government responses significantly challenged our life over the past year. On one side, restrictions, quarantine, limited social contacts, shutting down of access to support services and protection measures (wearing masks) helped protect us from SARS-CoV-2 infection. On the other hand, these restrictive measures brought negative effects too. The negative effects of COVID-19 pandemics over the population are important. Instead, the negative effects of the pandemic over the vulnerable groups (including families with children with special needs/SNC are severe). Several studies documented in families with SNC an increase in parental distress (Chen et al., 2020), children's problems (Chen et al., 2020), increases in caring-related difficulties and limitation of access to specialized support (Chen et al., 2020) which could relieve these problems (Hyseni Duraku & Nagavci, 2020). In this paper we present a psychological intervention program for reducing parental distress and the effects on reducing behavioral problems in children with special needs (SNC). We describe the effects of this program and how it can be used as an online parent-mediated intervention for reducing behavioral problems in SNC in the context of COVID-19 pandemics. Because in the pandemic specialist-mediated interventions for children's behavioral problems are limited, a parent mediated program for children's problems is a real advantage.

There are three main effects of COVID-19 pandemic and related measures over families with SNC: (1) high risk of severe illness and death for SNC, (2) child rearing pressure due to restrictions (masks, intense hand washing, quarantine) and changes in routine, (3) restricted access to specialized care (special school, support services such as specialized centers). It is largely known that well-functioning of SNC and their families depend on routines, efficient parenting, and access to specialized care, medical care, parent distress and mental problems. Because these requirements are affected by pandemics, it is expected that COVID-19 pandemics will severely affect the families with SNC. The pandemic studies confirmed these expectations

documenting an increase in parent distress and mental health problems (Chen et al., 2020; Dhiman et al., 2020; Wang et al., 2020, Zhang & Ma, 2020), an increased pressure for child rearing (Chen et al., 2020), an increase in negative parenting behaviors (Hyseni Duraku & Nagavci, 2020), an increase in children's behavior problems (Alhuzimi, 2020; Hyseni Duraku & Nagavci, 2020; Patel, 2020), and a reduction in the available support for child rearing (Patel, 2020). Moreover, it has been observed specific relations between these variables, caring pressure resulting in high parent distress and mental health problems (Chen et al., 2020). On other hand, high parental distress results in enhancing behavior problems in SNC. This effect may be due to a failure to manage behavioral problems (Hastings et al., 2002) or deficient initiation of positive behaviors or biased perception of the severity of the problems (Yorke et al., 2018). These relations are bidirectional: parental mental health and distress problems determine children's problems, which in turn further feed into parental problems. Routinely, these problems are primarily managed by specialists and secondarily by parents. One pandemic-related problem is the limitation of the possibility of face-to-face specialist-driven interventions. As a result, online parent-mediated interventions have a major potential to address this short-come. Moreover, COVID-19 increased parental distress (Wang et al., 2020; Zhang & Ma, 2020), this effect potentiating the increase in children's behavioral problems. Pre-pandemic studies that have investigated parental distress for parents of SNC concluded that parents of SNC have higher levels of distress than parents of children without special needs (Emerson, 2003) and that distress is a risk factor for both parental and children mental health (Hastings & Beck, 2004). Moreover, parental of SNC face more problems than parents of children without special needs.

Families with highly stressed parents were described as having higher risk for children psychopathology (Rossiter & Sharpe, 2001), higher use of coercive discipline and over control in disciplining (Floyd & Fhillipe, 1993), reduced efficacy of early rehabilitation interventions (Brinker, Seifer, & Sameroff, 1994) and of parent applied behavioral interventions (Baker, Landen, & Kashima, 1991). Generally, the impact of parental distress of parents of SNC resulted in efforts for developing interventions targeting the reduction of parental distress. Cognitive behavioral therapy is one of most investigated psychological intervention for mental health problems across various populations (Lyons & Woods, 1991; Chambless & Hollon, 1998) and types of distress (Pretzer & Beck, 2007). Furthermore, it is proposed as a promising intervention in reducing distress, anxiety, and depression for parent of SNC (Barlow et al., 2002). Yet, most of the investigated programs have been administered in a group format (Nixon & Singer, 1993; Greaves, 1997; Kirkham, 1993; Singer, Irvin & Hawkins, 1988). Although behavioral programs proved as efficient interventions in reducing child problems and parental distress, these studies did not target highly distressed families (Sanders et al., 2004). Given that high stress is affecting the application of behavioral methods by parents, a cognitive behavioral intervention that besides procedures for reducing distress includes methods for dealing with behavioral problems could be a viable solution for highly stress parents of SNC.

This paper describes a parenting program for reducing the distress of parents of SNC built on: (1) cognitive behavioral treatment for stress reduction and (2) problem-solving for children's problems that can be used in the context of COVID-19 pandemic. Furthermore, we describe the effect of the program of parent distress and reported children's behavior problems and to whom the problems are adapted to COVID-19 pandemic-related problems for parenting SNC (wearing masks, quarantine, etc.) and online-delivery. We expect that the program with result in

reductions in both parental distress and reported children behavioral problems compared to the parents who did not follow the program.

## **Methodology**

### **Participants**

Data from a large study regarding parental stress and children's behavioral problems from a randomized trial of 46 parents of SNC (27 intervention & 19 control) enrolled to a Disability Rehabilitation Centre were selected for the present study. Four parents were lost during the intervention. 42 parents were finally included in the analyses (23 from intervention group and 19 parents from the treatment as usual group). Average age for mothers was 35 years old, 24 the youngest and 46 the oldest. Exclusion criteria were bipolar disorder, depressive disorders with psychotic features, panic disorder, substance abuse, psychotic disorders, organics mental illness and mental retardation. Other exclusion criteria were parents who were enrolled in other form of psychotherapy at the date of the study or who needed hospitalization (Tiba, 2010).

### **Measures**

*Profile of Affective Distress Scale* (Macavei & Opris, 2007). Positive and negative emotions were assessed using the Profile of Affective Distress Scale (Macavei & Opris, 2007). The Profile of Affective Distress Scale is a 39-item scale that measures positive and negative affect and emotions (Macavei & Opris, 2007). Participants rated how much 39 emotional adjectives (e.g., happy, nervous, sad) described their mood *over the last week* on a 5-point scale from 1 (*very slightly or not at all*) to 5 (*extremely*). The Positive Affect (PA) and Negative Affect (NA) scales are have good reliability, (Cronbach's  $\alpha = .95$  and  $.92$  for the PA and NA scale respectively). Two additional items for guilt and regret were added.

*Problem Behavior Inventory*. The Problem Behavior measure is a 38-item inventory based on items from the behavioral scale of ICAP inventory (Bruininks et al., 1996) for this study to assess stress experienced by parents in response to various problem behaviors. For each item, parents indicated the frequency with which their child manifested specific symptoms over the previous week. Frequency was assessed using the following scale: A= no problems, B = once a week, C = 2 to 6 occurrences per week; D = 1 to 3 occurrences per day, E from 4 to 10 occurrences per day; F = more than 10 occurrences per day. These difficulties were grouped into four categories including externalizing behavior (12 items), repetitive, obsessive, and dangerous behaviors (15 items), avoidant/withdrawal behaviors (9 items); and emotional reactions (2 items). A total score was computed with higher scores indicating more behavior problems.

### **Program description**

The content of the program followed several directions from cognitive behavior therapy. The first step of building the program was developing a model of mechanisms involved in the distress of parent of SNC. The model is a cognitive model based on cognitive vulnerability factors involve in distress of parent of SNC (Greaves, 1997; Sanders et al., 2004; Kazdin & Weisz, 1998; Harvey et al., 2004), integrated with factors from contextual functionalism, grounded cognition and positive psychology. The procedures included are procedures tested in empirically supported programs applied to distress (Greaves, 1997; Kazdin & Weisz, 1998) and children's problems (Sanders et al., 2004).

### Program structure

The program structure followed the practical constraints for parents of SNC enrolled in a rehabilitation center: lack of time, lack of involvement of the father, low income. The group session lasted 2 hour and individual sessions are designed for 30 minutes. The group session included a description of the program, distress manifestations, cognitive mechanisms for distress and the corresponding methods for changing those mechanisms and reducing distress. Each parent received a manual of the program with exercises for each mechanism. Parents followed six thirty minutes long one-to-one individual sessions. Each session focused of one stress-related mechanism. After each session the parent have to apply the exercises discussed during the session and read the content of the next session. For instance, in session two each homework exercise is revised and the exercises for the next week are planned. Each step of the session is supported by the psychologist which provide summarize and feedback about each step.

Table 1. *The structure of individual sessions*

<i>Session 2</i>	<i>Session 3-6</i>
5 minutes Check the mood and the major events during the week (monitoring sheet)	5 minutes Check the mood and the major events during the week (monitoring sheet)
10 minutes Revise the stress model of group meeting, how stress manifests; then generate a problem list	10 minutes What they applied: check the exercise sheet and give suggestions
10 minutes First mechanism of stress is chosen and the application of corresponding change exercises are planned	10 minutes The topic of the session (analysis the stress mechanisms and the corresponding exercise)
-parents summarize the mechanism and how it affects stress	- parents summarize the mechanism and how it affects stress
-parents explore the effects of the mechanisms in their case	-parents explore the effects of the mechanisms in their case
-parents discuss what exercise they chose to do	-parents discuss what exercise they chose to do
-parents plan the application of the exercise to reduce distress	-parents plan the application of the exercise to reduce distress
5 minutes- The parents discuss the section of the manual they need to prepare for the next week	5 minutes- The parents discuss the section of the manual they need to prepare for the next week

The topics of each individual session were session one- secondary emotional distress (anxiety about anger, depression about anxiety, etc.), session two- problem solving for practical problems and accessing parent resources, session three cognitive distortions, session four on rigid evaluations, session five on activating the positive and session six and seven on procedures for preventing and responding to child behavioral problems. The sequence of the sessions is flexible, the priority of one session over the other depending on the importance of the problems for the parents (for parents with no support the session two may be the start of the individual sessions).

### Program adaptation to the COVID-19 pandemic

The process of adapting the program to the pandemic is natural because the program is highly structured manual driven intervention of procedures. The first group session may be applied both in group and individual format. Individual sessions two-seven may be easily applied on online systems such zoom, WhatsApp, messenger etc. For online administration the authors of the program suggest: (1) involvement of both parents or an additional support person for 30 minutes; (2) using the observation of direct parent-child interaction and the implementation of the planned methods; (3) offering feedback based on direct observation and retry of the techniques with integration of the provided feedback; (4) addressing emotional problems related to restrictions/quarantine and lack of support; (5) adding sessions for dealing with behavioral problems; (6) including the application of specialist suggested interventions-physical therapist; (7) focusing in the second session on problem solving and behavior activation for parent resources (adding two additional sessions: *wearing masks and repetitive hand washing*).

### *Wearing masks*

Wearing masks (WM) is a complex routine. The characteristics of SNC bring several considerations regarding the learning and consolidating the WM routine. Thus WM routine consists of three components: (a) learning to put the mask, (b) wearing the mask and not taking it off, and (c) taking off the mask. There are several suggestions for learning WM routine in SNC: (1) planning ahead and taking separate time for learning not just before going out; (2) distinguishing between three different behaviors-putting the mask, wearing and leaving it on the face and taking off the mask; (3) choosing the write learning moment; (4) choosing several learning methods that are best suited for the child ("*Maria (mother), let's go through several strategies that can help us teach Mike (the child) to wear the mask*"); (5) choosing the right methods to support the child behavior.

### *Learning procedure*

1. use clear instruction and explanation.
2. use incidental learning (e.g., when the child is interested about the mask, explain what it is, how we wear it and show positive reaction towards it).
3. use modelling and positive reinforcement plus explaining: for instance, the parents put their mask on and express positive reaction (e.g., "*Wow is super, I am safe now*").
4. use of forward chaining and backward chaining for learning putting the mask.
5. use physical support and discrete trial (e.g., help the hand of the child with your own hand) with physical support as discriminative stimulus an reinforcing the behavior when is done without the prompt (use verbal prompt-put it now by yourself) and reinforcement of correct behavior ("*Well done, you did it!*").

### *Behavior support and behavioral control of bad behavior (not wearing mask)*

6. use verbal support (parent prompts the child by telling him to wear the mask) or physical (parent use hands to support the hand of the child to put the mask) for putting or wearing the mask (e.g., verbal prompt -"*Mike... the mask!*", physical prompt-"*Mike, wait to help you put the mask!*").
7. use the behavior initiation routine (Sanders et al. 2004) (e.g., when the child miss to put his mask, the parent came close to the child, say his name, use a clear instruction, wait for child to do the instruction, repeat and double the instruction with a behavior change method such as

explanation, negative reinforcement or natural consequence-we don't go anywhere until you put your mask) –“*Mike, put the mask on, it's how we keep the viruses away and can enjoy playing today*”).

8. apply natural consequences (do not leave the house until he put the mask on).
9. use a reinforcement table.

Principles of application:

10. stimulus modification: use soft masks instead of rigid masks, avoid models of masks the set off negative reactions in children.
11. choose a time for learning when the child is calm.
12. use transitions and avoid interruptions from other activities.
13. avoid being in a hurry and do separate the time for learning from other activities.
14. make sure you have spare masks for the moments when the child is forgetting, tear apart the masks.
15. apply calming routine by parents by correcting unreasonable expectations (instead of saying myself that I thought him to wear the mask so he must wear it, breath, remind to accept he is forgetting and offer support for the child in helping find the mask).
16. anticipate obstacles and always generate solutions to the obstacles (throw the mask, tantrum, cry, refuse, etc.).

The sequence of the parenting session in the program includes: (1) setting the topic of the agenda as learning to wear the mask (“*Do you think it would help to find several solutions to stimulate Mike to wear the mask? / You have told me that it is a problem with wearing the mask*”); (2) generating specific solutions based on the general solutions abovementioned (“*Let's go through several solutions that helps us to teach Mike to more easily to wear the mask*”); (3) demonstration of the learning solution by the psychologist and prompting the parent to apply the solution (e.g., incidental learning, “*When Mike show curiosity for the mask we can tell him-Mike have you ever tried to wear the mask as I am? Do you want to put it on by yourself? Watch me...*”); (4) discuss the possible obstacles and corresponding solutions, children mood, previous rejection of the mask etc. (e.g., “*Which obstacles may appear and what can we do about them?*”); (5) put it in practice and monitor the application of each method; (6) following the monitoring chart, giving feedback and planning the application of the next method. Similar methods are used for learning intense hand washing.

### **Study procedure**

In the initial study, parents of SNC were contacted by posters about the study at the Rehabilitation Centre in Oradea, Counselling center and special schools, Oradea, Bihor County. The parents contacted the principal investigator (AT) and then they were appointed for the first session. They signed the agreement and the informed consent and then the forms for the first evaluation. The study has last two years with three rounds of selection. Parents were randomized to two groups, an intervention group and a treatment as usual for parents that followed the services of the rehabilitation center as usual. A randomized clinical trial with two groups mixt design was carried on. An independent variable was intervention and repeated measure was the time of administration: before and after the intervention. Main dependent measures were parental distress and reported child behavior problems.

## Design and variables

A mixt 2X2 design with two independent samples (intervention and control group) and two repeated measures (pre-test, post-test) was used. Dependent variables were parent distress measure with PDA scale and parent reported child behavior problems.

## Results

Table below describes outcome data regarding main dependent variables.

Table 2. Means and standard deviations of the dependent measures

Variables	Intervention	Control
Distress-PDA Before intervention	68.14 (17.28)	67.36 (17.55)
Distress-PDA After intervention	46.30 (15.06)	69.15 (18.85)
Behavior problems Before intervention	71.07 (17.38)	69.84 (14.14)
Behavior problems After intervention	49.08 (16.12)	70.36 (14.62)

Note: PDA-profile of affective distress. Standard deviations are in parentheses.

To evidence the effect of the cognitive behavioral program for the parents who followed the program compared with the parents from the treatment as usual, we used ANOVA repeated measures and pair to pair comparisons by *t* tests. For the distress measure, ANOVA test showed a main group effect  $F(1,40)= 6.10$  ( $p= .01$ ,  $p < .01$ ) which suggests that the parents who followed the program differ regarding the stress level compared to the parents from treatment as usual. Post-hoc tests showed that this difference is significant only posttreatment ( $t= 4.36$ ,  $p < .01$ ), no significant difference being observed at pre-test ( $p > .05$ ). An interaction effect between group and time was observed for distress measure  $F(1,40)= 31.68$  ( $p= .00$ ,  $p < .01$ ).

As expected the intervention group showed a significant difference between the time of measure having a lower level of distress after the intervention ( $t(22)= 7.11$ ,  $p < .01$ ). No significant difference was observed for the control group. A separate ANOVA was carried out for analysis of the effects of the intervention of the parent reported children's problems. The results showed a significant group effect  $F(1,40)= 91.29$  ( $p= .00$ ,  $p < .01$ ) for behavioral problems, which suggests that the parents who followed the program differ regarding the reported behavioral problems compared to the parents from treatment as usual. Post-hoc tests showed that this difference is significant only posttreatment ( $t= 4.48$ ,  $p < .01$ ), no significant difference being observed pre-test ( $p > .05$ ).

As expected the intervention group showed a significant difference between the time of measure having a lower level of reported behavioral problems after the intervention ( $t(22)= 9.55$ ,  $p < .01$ ). No significant difference was observed for the control group between pre and post-test ( $t= .59$ ,  $p > .01$ ).

## Conclusions and Discussions

We described a parenting intervention for parents with high levels of distress regarding behavior problems of their SNC. It is a manual-guided intervention that can be easily applied on an online format and adaptation to the specific problems of the COVID-19 pandemic is described. Results showed a reduction in both the parental distress and reported behavioral problems of SNC. There are several interpretations of the reduction of children's behavioral problems. One explanation is that parents report fewer problems because the problems actually were reduced in frequency. In the present study, the children's behavioral problems have been measure by parent self-report only, so we cannot draw firm conclusions about this explanation. Yet, this explanation is in line with documented effects of parenting interventions over parent distress and child's behavior problems (Yorke et al., 2018). We carried out an exploratory analysis of the possible mediators for this relation (Tiba & Vădineanu, 2010). Exploratory analyses revealed that when controlling for various factors (locus of control, metacognitions, social support, irrational beliefs) the effect of the intervention on behavioral problems is mediated by the social comparisons of the parents ( $\beta = -.55$ ,  $p < .01$ ). So, it is possible that after the program, the parents do less unfavorable comparisons of their children's behavior with that of other children and have a tendency to consider the reactions of their children as normal behavior and not problem behavior (Tiba, 2010). This suggests that at least one path by which the program reduces behavioral problems is by changing negative comparisons. Thus, we suggest that changing social comparisons besides reducing distress is important. Social comparisons may be a way by which parents describe the child's reaction as a problem. Normalizing and knowing how to react to these problems may result in a tendency to consider the children's reaction as non-problem behavior. For instance, when the child is *crying*, a distressed parent may consider it as a behavior problem reacting with low frustration tolerance and negative comparisons with other parents. When parents are not under high levels of stress and correct their negative thoughts, they can consider crying as normal and know what to do in response to the crying (such as offering emotional support or guiding the child toward an activity). Furthermore, it is possible that the parents evaluate the children's behavior as problems or normal behaviors based on social comparisons.

In the context of COVID-19 pandemic there may be two main situations: (1) parents of SNC make unfavorable comparisons with other children and families and (2) parents can make favorable or neutral comparisons. Parents who make unfavorable comparisons may exaggerate the perceived problems, emotionally react to behavior instead of using support or disciplining methods (e.g., when the child refuses to eat parents can compare them with other children who do not refuse to eat, do not have special needs and a result to consider the behavior as a problem and to negatively react-use discipline instead of support- reaction that can amplify the behavior problem-the child persist in refusing). Parents who do not make unfavorable comparisons may respond with low frustration tolerance and apply a proper method of responding to child behavior (e.g., when the child refuses to eat and shouts, the parent can consider that is normal – all the children do this-and ignore the reaction waiting for the child to ask for food-proper reaction).

Helping parents to correct unfavorable comparisons may help them not to exaggerate the children's problems and to consider minor problems as normal behavior. Moreover, negative comparisons of the parents may directly result in children's problems. For instance, instead of providing support, a parent who expects a child not to tear off the mask (because other children do not) may use discipline instead of physical support, and this may result in opposition and

escalation of behavior problems from the child. We suggest that the way parents construct the reactions of the children as problem reactions is important and depends on the mood, emotions, cognitive evaluation, comparisons, and the context of assessing and reporting the problems. In turn, the perceived problems may determine the reactions of the parent and subsequent effects of behavior problems.

### **Recommendations for the Parent-Mediated Intervention in the COVID-19 Pandemic**

ased on this study, we make the following recommendations for the parent-mediated intervention for behavioral problems: short parent-focused interventions are suitable to help parents of SNC; intervention should include a focus on reducing parent distress; normalizing bad behavior is required; the program should include problem-solving focused on wearing the mask; the program should include problem-solving focused on intensive hand washing; the focus on parent resources is important; assessment of the degree of which negative comparisons are increased by restrictions; increase of tolerance of unwanted behaviors; give priority for methods aimed at changing the environment.

### **Limits of the Study**

Several limitations should be considered. The results should be interpreted taking into caution the limited number of participants. Lack of active control group which includes a support intervention added to treatment as usual also limits conclusions about the specificity of the effect of the intervention. Furthermore, the conclusions should be limited to mothers of SNC. It is possible that in the case of fathers the program results in different effects.

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