

PORTUGUESE  
ASSOCIATION



# How CDG impacts patients and family members

Luísa Barros & Carolina Cardão  
Universidade de Lisboa  
Faculdade de Psicologia





# What are coping strategies?

When facing new and difficult situations, people experience **stress and other emotional negative reactions** (anxiety, depression, helplessness, frustration).

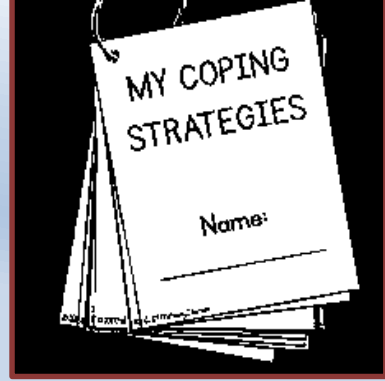
These reactions result from the subjective evaluation of the situation as threatening, harmful, discouraging, or demanding more resources than those available to us.

The experience of parenting a child with a chronic condition is filled with situations parents experience as threatening or too demanding.

Continuous stress can impact our health and wellbeing.

# Coping

- Coping is how we organize our response to these situations, to reduce overall stress and emotional disturbance.
- **Problem-focused** includes actively planning or engaging in a specific behavior to overcome the problem, i.e., *searching for information, learning new skills, planning, obtaining instrumental support*;
- **Positive reappraisal** attempts to change the meaning of the situation by *positive reframing, normalization*;
- **Emotion-Focused** attempts to regulate the emotions evoked by *positive thinking, minimizing, spirituality and hope, distraction*.



# Aims of the study and methodology

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Psychological adaptation  
to the experience of living  
with CDG



- ✓ Daily demands and challenges
- ✓ Coping strategies

Qualitative, exploratory and descriptive study

Semi-structured interviews  
with family members



Transcription of the verbal  
data



Analysis of the data and search  
for main categories



Generation and organization of  
the data in codes



Qualitative analysis

# Participants

Type of CDG	Number of participants (Family Members)	Number of CDG patients
ALG11-CDG (CDG-Ip)	1	1
DPAGT1-CDG (CDG-Ij)	1	2*
DPM1-CDG (CDG-Ie)	3	1
PIGN-CDG	1	1
PMM2-CDG (CDG-Ia)	34	25*
<b>Total</b>	<b>40</b>	<b>30</b>

\*includes siblings

Kinship with the patient	Number of participants
Mother	26
Father	7
Sibling	5
Grandparent	2
<b>Total of family members</b>	<b>40</b>



# Daily life with CDG

## ▪ Demands and challenges

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### **Disease**

- Understanding the disease
- Daily management of the disease

### **Relationship with health & Education professionals**

- Professionals lack of knowledge about CDG
- Assuming the role of “expert” and the responsibility of the disease management
- No specialist available and accessible

### **Difficulties in emotional regulation**

- Anxiety and specific fears
- Sadness
- Multiple Worries
- Loneliness

### **Financial burden**

- High cost of disease management
- Only one parent working
- Difficulties in receiving financial support

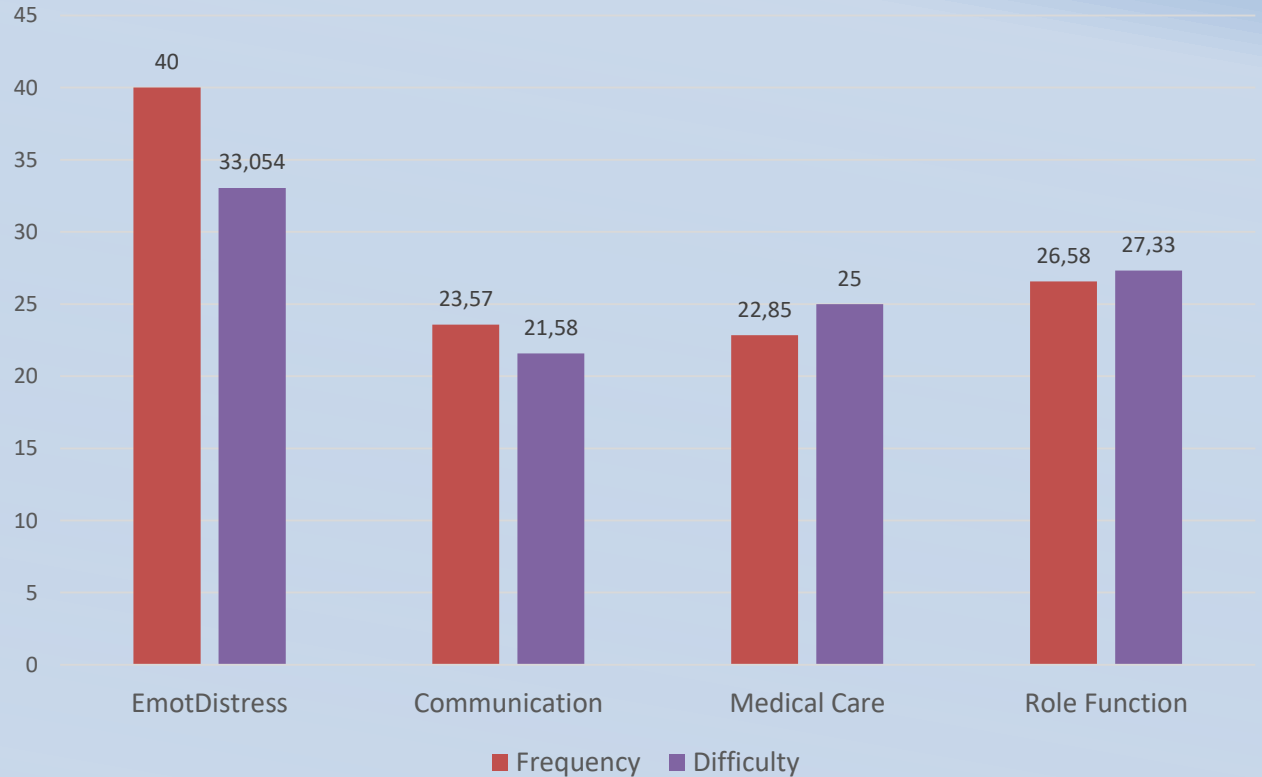
### **Lack of support**

- Parents as only caregivers
- Difficulties in the social integration of the patient
- Time management difficulties- need to have some free time to social leisure
- Friends turn away

# Parenting Stress in Chronic Illness

Parents of CDG patients answered  
The **Pediatric Inventory for Parents**

PMM2-CDG- 23  
Other CDG- 3

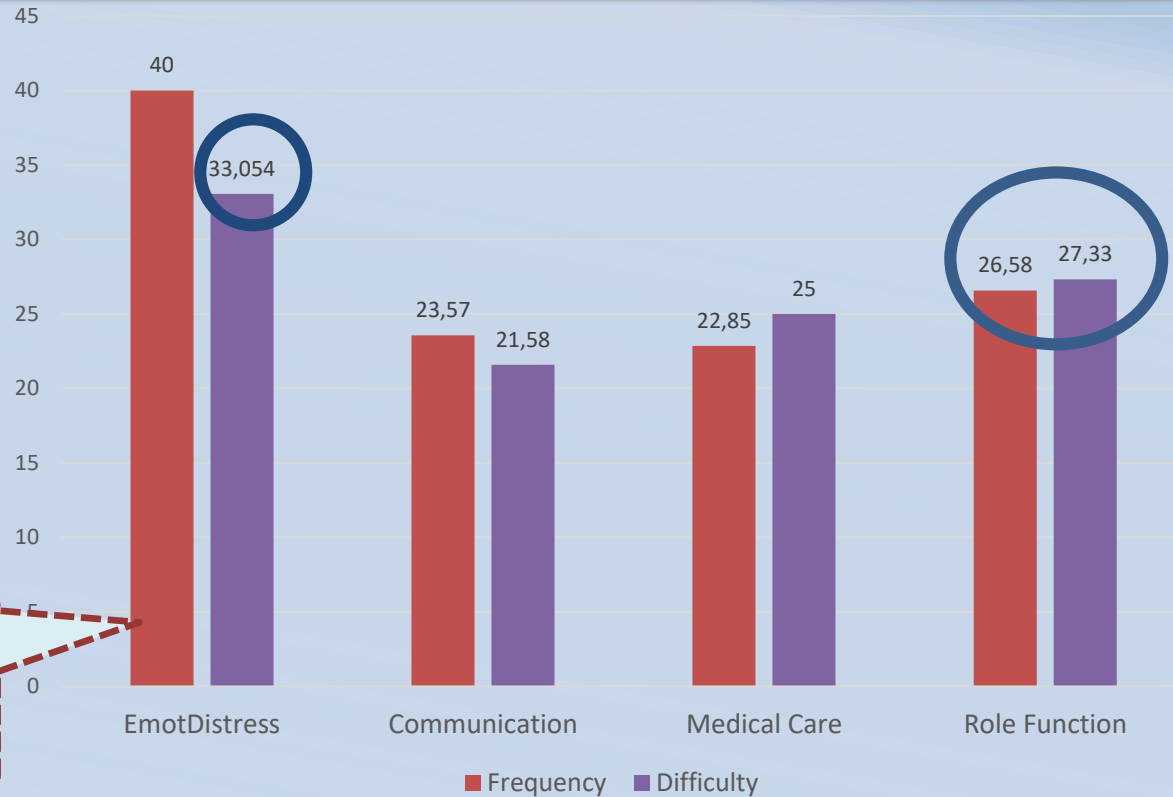


# Parenting Stress in Chronic Illness

Parents of CDG patients answered The **Pediatric Inventory for Parents**

PMM2-CDG- 23  
Other CDG- 3

Results are higher comparing to parents of cancer patients, obesity and IBD; except for Emot.Dist-Difficulty





# Daily life with CDG

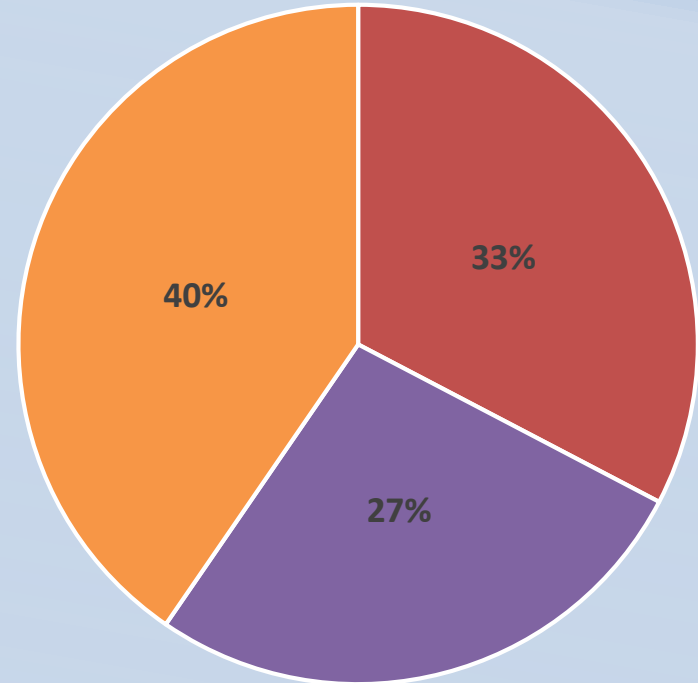
- Coping strategies

## Parents described a balanced set of coping strategies:

Aiming to solve the problems directly;

Changing the subjective meaning of the situation or

Searching for emotional balance

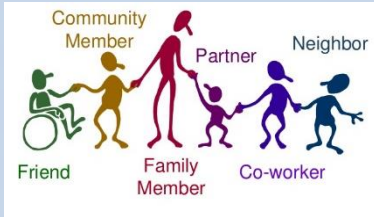


■ Emotion Focused   ■ Reappraisal   ■ Problem-Focused

# Daily life with CDG

- External Resources most valued

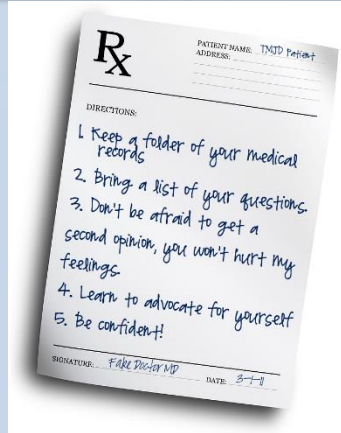
## Social support (38,10%)



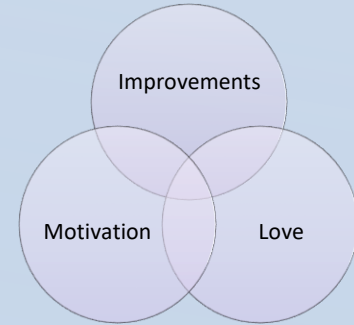
*“Having the online group with people with the same disease helps to eliminate the loneliness, we can ask each other questions and share our experiences, it’s tremendously helpful.”*

*“There is a small association with some CDG families, and we meet every year and it makes us feel that we belong somewhere, that other people are facing the same issues.”*

## Health and social services (29,17%)



## The patient him/herself (15,48%)



*“She is very positive, with a good mood, she is a blessing”*

*“He is developing really well and it is a victory for all of us!”*

*“Each time I think I can't make it, I continue because of the love she gives me.”*

# Conclusions

- Parents of children with CDG of all ages experience multiple stressors related to the illness and the need to balance their parenting and caretaker role with other personal roles;
- Parents adapt by using a diversity of effective coping strategies, showing their ability to adapt to the challenges.
- CDG Associations and healthcare/educational providers play a critical role in this adaptation.