5th October, 2021

Parents working as a team when a child has a chronic condition: How does it make a difference?

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Pediatric chronic conditions: Challenges

Pediatric chronic conditions
(e.g., Cancer, Epilepsy)

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Disruptions in the family system
(e.g., rearrangements of family routines, responsibilities and roles)

Long & Marsland, 2011; Santos et al., 2017

The role of caregiving may interfere with **parenthood**
Changes in childrearing and discipline strategies
Increased difficulties in parent–child relationship

Norberg & Steneby, 2009; Rodenburg et al., 2013

Balancing family and child's needs may be **burdensome**

Patterson et al., 2004; Shore et al, 2009

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Pediatric chronic conditions: Challenges

Parents and **children**

are at a higher risk of developing

mental health problems

Cancer: ↑ anxiety, depression

Sultan et al., 2016; Vrijmoet-Wiersma et al., 2008

Epilepsy: ↑ anxiety, depression

Ferro et al, 2011; Jones & Reilly, 2016

Cancer: ↑ depression, anxiety, behavioural problems Friend et al, 2018; Lund et al, 2013

Epilepsy: ↑ depression, anxiety, behavioural problems Modi et al, 2017; Wagner et al., 2015

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Family resources: Parental mutuality

- Family's response to disease-related challenges influences parent's and children mental health

  Deatrick et al., 2006, Knafl et al, 2013

- Strengths-based approach value the identification of the **family resources**

  Kazak et al, 2009; Rolland & Walsh, 2006

PARENTAL MUTUALITY (PM)
- Parents work as a team in managing the health condition
- Spouse perceived as supportive
- Shared view of the seriousness of the condition and how it should be managed

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Children and parents' psychological adjustment

Deatrick et al., 2006; Knafl et al., 2012

Kim & Im, 2015; Mendes et al., 2016

Mechanisms through which PM influences psychological adjustment ?

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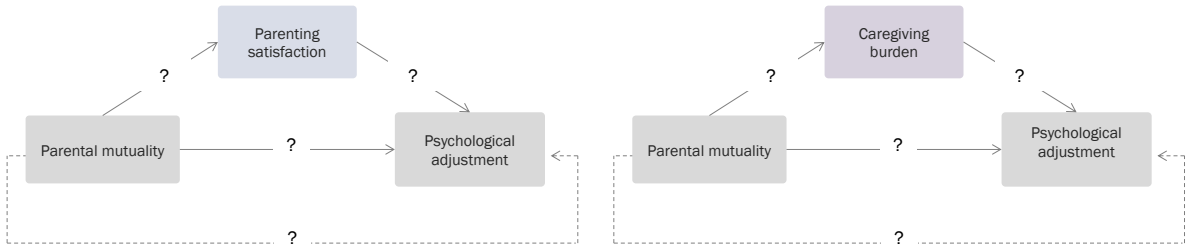
Studies Aims

Examine the direct and indirect links between **parental mutuality** and **psychological adjustment** (parents and children) via parental and caregiving variables (two mediational paths explored)



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Methods

PARTICIPANTS

Cancer study

- 201 parents (85% mothers)
- Children with cancer aged between 8-20 years old (*M*=13.25; *SD*=3.45)
- Mean time since diagnosis (months): 30.06 (*SD*=26.60)

Epilepsy study

- 179 dyads of children with epilepsy (52%boys) and parent (85% mothers)
- Children aged between 8-20 years old (*M*=12; *SD*=3.15)
- Mean time since diagnosis (months): 53.5 (*SD*=43.3).

INCLUSION CRITERIA

- Parent referred to as the primary care provider for health-related issues (cancer and epilepsy) and currently in a relationship (cancer);
- Child with a clinical diagnosis of cancer/epilepsy aged ≥ 8y, diagnosed for at least 3 (cancer) or 6 (epilepsy) months.

EXCLUSION CRITERIA

- Comorbidity with other chronic illness, major developmental disorder or end-of-life care/issues.

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Methods

RECRUITMENT

- Consecutive sampling (may 2013 – december 2017)
- 5 NHS hospitals in Portugal
  - Cancer sample: IPO Porto, IPO Lisboa;
  - Epilepsy sample: CHUC (Coimbra); HGO (Almada); CHLP (Leiria)

STUDIES DESIGN

- Cross sectional

ETHICS

- Ethics Committees approvals;
- Informed consent / assent (children ≤ 12y).

STATISTICAL ANALYSIS

- Mediation models were tested with PROCESS macro for SPSS.

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Methods

	VARIABLE	MEASURES	Cronbach alphas (C/E)	Cancer Study (C)	Epilepsy Study (E)
PARENTS	Parental Mutuality	**Family Management Measure** (FaMM; Knafl et al., 2011) Subscale Parental Mutuality (8 itens)	.80/.86	√	√
	Parental Satisfaction	**Parenting Sense of Competence** (PSOC; Johnston & Mash, 1989) Subscale Satisfaction (9 itens)	.71	√	
	Careviging Burden	**The Revised Burden Measure** (Montgomery & Kosloski, 2006) Burden – Total (16 itens)	.90		√
	Psychological Adjustment	**Hospital Anxiety and Depression Scale** (HADS, Zigmond & Snaith, 1983) Subscale Anxiety (7 itens) Subscale Depression (7 itens)	.83 .77	√	
		Brief Symptom Inventory (BSI; Derogatis, 1993) Subscale Anxiety (6 items) Subscale Depression (6 items)	.87 .86		√
CHILDREN	Psychological Adjustemnt	**Strengths and Difficulties Questionnaire** (SDQ, Goodman, 2001) Psychological Difficulties - Total (20 itens)	.80		√

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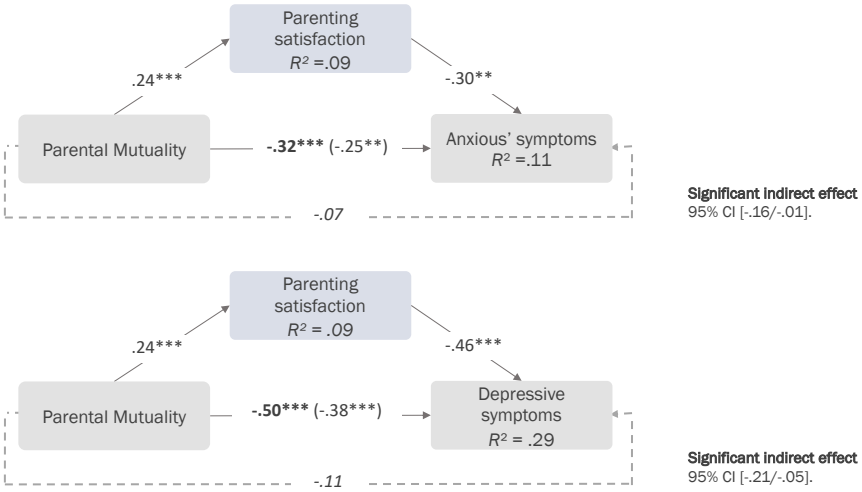
Results

CANCER STUDY
N = 201 parents



Note.
Standardized coefficients are presented. The values inside parentheses represent the direct effect. Values in italic represent the indirect effect. Values in bold represent total effects. *p< .05, **p<.01, ***p<.001

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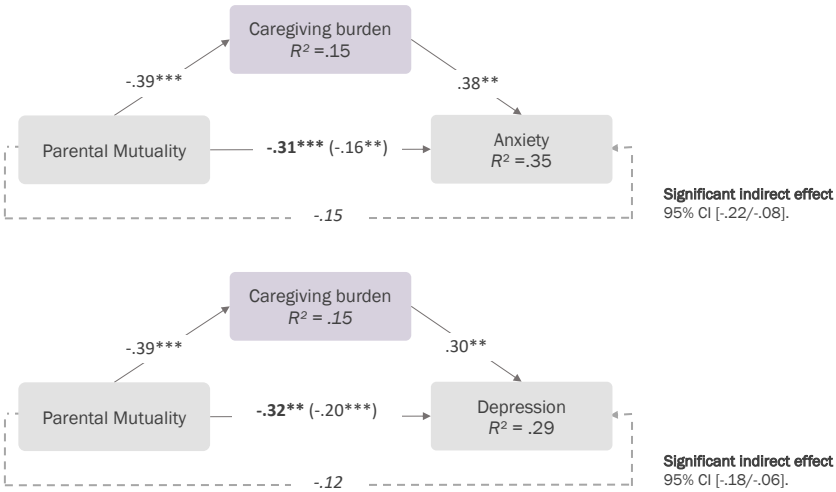
Results

EPILEPSY STUDY
N = 179 parents



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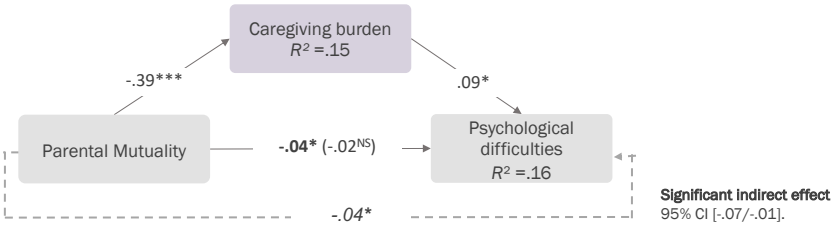
Results

EPILEPSY STUDY
N = 179 children



Significant indirect effect
95% CI [-.07/-.01].

Note.
Standardized coefficients are presented. The values inside parentheses represent the direct effect. Values in italic represent the indirect effect. Values in bold represent total effects. *p< .05, **p<.01, ***p<.001

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Discussion

Benefits of parents working as a "synchronized" team
to address the challenges posed by their child's chronic condition

PARENTING LEVEL
↓
Promoting a firmer sense of parental satisfaction (cancer)

CAREGIVING LEVEL
↓
Reducing burden (epilepsy)

INDIVIDUALS' PSYCHOLOGICAL FUNCTIONING LEVEL
↓
Directly and indirectly for parents (cancer, epilepsy)
Indirectly for children (epilepsy)

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Implications for practice

- Need for **family- and parent-based interventions**
- Promoting **parental mutuality** as a possible avenue to improve family life, parental satisfaction, reduce burden and promote individual's psychological adjustment (parents and children)

RECOMMENDATIONS FOR CLINICIANS

1. Routinely address parental mutuality issues:
   - Discrepancies in parents' perception of the seriousness of their child's condition
   - Burden and (un)shared roles and responsibilities
2. Assist the parental dyad to discuss and work cooperatively/as a team

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How does it make a difference?

Thank you

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