



Family factors as predictors of the quality of life and the emotional distress in Children with Cystic Fibrosis



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INTRODUCTION

- Due to recently developed therapies, **patients' life expectancy with CF today is in the early 40s.**
- As a result, medical providers in CF Care Centers seek not only to **improve patients' health** but also to **enhance their quality of life (QOL).** Accordingly, QOL of school-aged children with CF is relatively under-investigated.
- The role of **family contextual variables** has received increased attention **as predictors of child adjustment to illness.** Evidence exists that parenting & parent-child relationship factors are related to children's emotional development and thus may be life-course determinants in their health.
- **To date, no study has quantitatively investigated parental factors, particularly with respect to paternal variables, associated with the QOL of children with CF.**

OBJECTIVE

We investigated the association of parenting stress, children's emotional distress, family functioning, and fathers' involvement in disease management to QOL in children with CF.

METHOD

Participants

Using a cross-sectional design, this study recruited 25 families of children with CF from four different CF Centers (2 in Belgium & 2 in USA).

Inclusion criteria: (a) A diagnosis of CF for at least one year; (b) Aged 8 to 12 years; and (c) Both parents willing to participate.

Measures

- **Parent questionnaires**
 - **Parenting Stress Index – Short form (PSI-4-SF; Abidin, 2012):**
 - **Factor I** – Parental Distress (PD); **Factor II** – Parent-Child Dysfunctional Interactions (PCDI); and **Factor III** – Difficult Child (DC)
 - *Higher score = more parenting stress*
 - **Family Environment Scale (FES; Moos & Moos, 1981):**
 - **5 subscales:** Cohesion; Expressiveness; Conflict; Organization; Control.
 - *Higher score = more the dimension is present in the family*
- **Dad's Active Disease Support (DADS; Wysocki & Gavin, 2004):**
 - **Mother's form:** mother's rating of their male partner's involvement in CF management tasks
 - **Father's form:** father's rating of his own involvement in the same tasks
 - 2 scores: **amount of support** (*higher score = more support*) and **helpfulness of support** (*higher score = more the support is helpful*)
- **Quality of Life Systemic Inventory (ISQV; Dupuis et al., 1989):** *lower score = better QOL*
- **Child questionnaires**
 - **State-Trait Anxiety Inventory (STAIC; Spielberger, 1973):** *higher score = more depression*
 - **Children Depression Inventory (CDI; Kovacs & Beck, 1977):** *higher score = more anxiety*
 - **Quality of Life Systemic Inventory for Children (ISQV-E; Etienne et al. 2010):** *lower score = better QOL*

RESULTS

Descriptive statistics & Comparison with normative data

	Female **		Male		Norms *		p values	
	N	Mean (SD)	N	Mean (SD)	Female	Male	Female	Male
PARENTS								
PSI-4-SF								
Total	25	78.92 (24.08)	24	79.92 (24.43)	59 th perc.	60 th perc.	Normal range	
PD	25	26 (9.43)	24	24.75 (8.07)	55 th perc.	50 th perc.	Normal range	
PCDI	25	24.2 (9.39)	24	25.88 (9.40)	59 th perc.	67 th perc.	Normal range	
DC	25	28.72 (8.21)	24	29.29 (9.24)	62 th perc.	62 th perc.	Normal range	
FES								
Cohesion	25	5.92 (1.18)	24	6.08 (0.97)	6.61 (1.36)		.01	.05
Expressiveness	25	5.76 (1.33)	24	5.38 (1.13)	5.45 (1.55)		ns	ns
Conflict	25	2.76 (0.97)	24	3.08 (1.14)	3.31 (1.85)		ns	ns
Organization	25	4.72 (1.70)	24	4.5 (1.29)	5.41 (1.83)		.06	.02
Control	25	3.68 (1.38)	24	3.58 (1.72)	4.34 (1.81)		.07	.03
DADS								
Amount	25	67.63 (22.54)	24	65.89 (15.68)	64.9 (20.5)	66.6 (18.0)	ns	ns
Helpfulness	25	76.30 (23.06)	24	66.23 (15.25)	75.8 (21.9)	70.6 (18.2)	ns	ns
Total	25	143.93 (40.81)	24	132.12 (25.02)	141.0 (39.6)	137.3 (30.6)	ns	ns
ISQV	25	5.23 (3.30)	22	4.24 (2.86)	3.83(3.97)		ns	ns
CHILDREN								
STAIC								
State	11	27.91 (1.04)	14	29.36 (0.93)	30.7 (6.01)	31 (5.71)	ns	ns
Trait	11	31.09 (1.81)	14	34.57 (1.60)	38 (6.68)	36.7 (6.32)	<.001	ns
CDI	11	7.73 (5.64)	14	10 (6.04)	<19		Absence of symptoms	
ISQV-E	11	2.58 (3.52)	14	4.62 (4.83)	2.1 (2.04)		ns	<.001

* Comparison between our sample means and normative data from:

• Abidin, 2012 (PSI-4-SF): Normal range for scores is within the 16th to 84th percentiles. Scores in the 85th to 89th percentiles are considered high, and scores in the 90th percentile or higher are considered clinically significant; Moos & Moos, 1981 (FES); Wysocki & Gavin, 2004 (DADS): sample = parents of children with pediatric chronic medical conditions; Dupuis, Marois & Etienne, 2012 (ISQV); Spielberger, 1973 (STAIC); Kovacs, 1983 (CDI): absence of depressive symptoms <19; Etienne & al. 2010 (ISQV-E)

** Comparison between females and males in our sample:

• All mean scores between females and males were subjected to a dependent sample t-test and **none were significantly different. Nevertheless, the difference in means** between females and males regarding the total and helpfulness score of DADS, the QOL in parents as well as the QOL in children **is clinically relevant.**

Correlations between parents' variables and children's variables

	Boys			Girls		
	STAIC-Trait	CDI	ISQV-E	STAIC-Trait	CDI	ISQV-E
Mothers						
PSI-4-SF – Total	.44	.46*	.46*	.14	.28	.67**
PSI-4-SF – PD	.34	.37	.29	-.16	-.14	.36
PSI-4-SF – PCDI	.39	.49*	.47*	.19	.38	.38
PSI-4-SF – DC	.50*	.42	.52*	.41	.55*	.79**
Quantity DADS	.56**	.21	.20	-.36	-.46	-.05
Quality DADS	-.06	-.14	-.05	-.18	-.61**	-.23
DADS total	.26	.03	.07	-.31	-.58*	-.14
ISQV	.25	-.07	-.05	.29	.29	.22
Fathers						
PSI-4-SF – Total	-.13	.38	-.21	.53*	.10	.64**
PSI-4-SF – PD	-.31	-.20	-.40	.29	.10	.36
PSI-4-SF – PCDI	-.11	.06	-.16	.52*	.17	.69**
PSI-4-SF – DC	.06	.22	-.03	.59*	.16	.66**
Quantity DADS	.38	.25	-.08	-.09	-.23	.15
Quality DADS	-.03	-.23	-.44	.19	.06	.10
DADS total	.22	.04	-.27	.11	-.09	.17
ISQV	-.33	-.59**	-.65**	-.31	-.28	-.20

DISCUSSION

- **Parents of children with CF** were similar to the normative sample regarding parenting stress, parental QOL, and rating of father's involvement in the management of the disease. However, parents of children with CF showed a **poorer cohesion, less organization** and ran the family life with **less rules and procedure** than the normative sample.
- Interestingly, this study demonstrated **no differences between mothers and fathers** of a child diagnosed with CF. This observation may be due to small sample size.
- Children with CF reported **no anxious or depressive symptoms.** However, **boys with CF** demonstrated a significant **decrease in their QOL** compared to the normative sample whereas girls with CF had a similar QOL than healthy children.
- Among **mothers** of children with CF, **parenting stress was related to QOL in children.** This phenomenon is more pronounced in the girls with CF. Also, **mothers' perception of fathers' involvement** in the disease is related to **children emotional distress.**
- Among **fathers** of children with CF, **parenting stress** is positively correlated to **QOL in girls** with CF; whereas **QOL in fathers** is negatively correlated to **QOL in boys** with CF.
- **In future research,** it might be interesting to run moderation and mediation analyses to examine the indirect effect of mothers' and fathers' variables on the child's QOL.

CONCLUSION

Information about fathers is underrepresented in pediatric psychology research. However, interest in impact of parental adaptation on children's adjustment to chronic disease is on the increase. The results of this study are expected to contribute to the understanding of how both parents play a role in the QOL and emotional adjustment of school-aged children with CF.

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