



Quality of life and family impact of a life threatening condition on caregivers of children receiving palliative care

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Quality of life

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Background

Taking care of a child with a life threatening condition is a demanding task for caregivers. Getting to know their quality of life and the family impact they may have would enable better health interventions. There were no previous studies in the country.

Aims

To evaluate the health related quality of life and the family impact on caregivers of children receiving palliative care in the population assisted in the pediatric palliative care unit at the national reference pediatric hospital.

Metho ds

- Observational, descriptive and transversal study
- January – July 2019
- Sample: caregivers of hospitalized children
- Instrument used: PedsQL Family Impact Module
- Psychosocial form for sociodemographic characteristics
- SPSS version 20 for statistical analysis
- Cronbach's α coefficient analysis for instrument's reliability
- Descriptive statistics
- Two ethics committee approvals
- None financial support

Results

- Data from 70 caregivers of children from 1 month to 18 years old
- Primary caregivers: mothers 92.9 %
- Median age: 32 years old (range 15 years old – 55 years old)
- Family Impact Module obtained a good internal consistency
- The self reported HRQOL evaluation of the caregiver obtained a mean score of 60,4 with a standard deviation of 21,5. The Worry and Daily Activities dimensions were the most affected and Family Relationships was the least affected

Description of the scores of the Family Impact Module of caregivers of children from 1 months to 18 years old.

n =70	MEAN	MEDI AN	DEVIATI ON	MiNIM UM	MAXIM UM	CRONBAC H'S ALPHA
Physical	61,6	66,6	28,4	0	100	,86
Emotional	61,0	60,0	26,1	0	100	,78
Social	63,5	75,0	31,3	0	100	.81
Thought and concentrati on	65,6	75,0	30,3	0	100	,90
Comunicati on	57,1	54,1	32,6	0	100	,74
Worries	45,5	45,0	24,7	0	100	,70
Daily activities	56,0	58,3	32,5	0	100	,74
Family relationshi ps	70,5	80,0	29,0	0	100	,86
SUMQOL	63,0	70,0	24,0	6,25	97,50	,93

Working situation of the caregiver		
	Frequency	Percentage
Have a job	10	14,29
Unemployed	13	18,57
Housewife	42	60,00
Other activities: srtudents,	4	5,71
Did not answer	1	1,43
Total	70	100,00

Conclusions

- Caregivers main concern is the future of their child and the organization of daily life while family relationships may act as a source of protection. A limitation of the study is general conclusions can not be made, but it is a contribution to get closer to the needs of these families.

Listen, really listen!

“I don’ t have any problem to tell doctors how I feel... but they never ask, if they asked I would tell them how I feel...”

So first of all, we should
ask!



Grazie !

