Preliminary results of the Quality of Life Systemic Inventory for children in Pediatric Cystic Fibrosis

A tool for clinical interventions?

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1 INTRODUCTION

Quality of life (QOL) has become an important treatment goal in chronic diseases, including cystic fibrosis, as longevity has increased and medical research has progressed (Abbott & Gee, 2003; Gee, Abbott, Conway, Etherington & Webb, 2003). However, using QOL as a concept for children has only recently been recognized as useful. Consequently, QOL of children aged 6 to 12 years is underinvestigated (Wallander & Schmitt, 2001). Specific measures are generally used to assess QOL of patients with CF. Nevertheless, these measures do not allow comparison between CF and healthy children. To overcome this drawback, we promote the development of an assessment tool of QOL based on a modular approach. This study examined the generic and CF-specific QOL in CF children using a tool based on a modular clinical approach.

2 METHOD

Participants

Sample consisted of 12 CF children and 12 healthy children aged 8 to 12 years, matched by age and sex.

Measure

The Quality of Life Systemic Inventory for Children (**QLSI-C;** Dupuis, Perrault, Lambany, Kennedy & David, 1989) assess both generic (20 items) and CF-specific (6 items) QOL. CF-specific module is empirically created from CFQ-R and discussion with medical staff. QLSI-C is a dynamic tool, using a VAS.

QLSI-C considers **QOL** (gap score) like the difference between the **present situation** (state score) and the **expectations** (goal score). This difference is weighted by the **importance** (rank score) that children assign for each life domains.

Generic items (20 items)		CF-specific items (6 items)
1. Sleep	11. Relation with my siblings	21. Emotional state
2. Eating	12. relation with my friends	22. Treatment constraints
3. Physical pain	13. How my friends describe me	23. Physical functioning
4. Health	14. School	24. Respiratory symptoms
5. Clothes	15. School performance	25. Digestive and weight symptoms
6. Body image	16. Sport	26. Relation with medical staff
7. Bedroom	17. Leisure	
8. Relation with grandparents	18. Autonomy	
9. Relation with my mother	19. Obedience to authority	
10. Relation with my fathers	20. Frustration tolerance	

3 RESULTS

Generic module VS CF-specific module

- Global scores in CF-specific module is correlated with global score in generic module for CF children (r=0.66 to 0.96).
- Assessment of QOL is the same for both generic (M=3.76) and CF-specific (M=3.76) module (p=0.53).

CF childrenVS healthy children

	Children with CF N = 12	Healthy children N = 12			
	M(SD)	M(SD)	dl	F	p
STATE	18,77 (2,78)	15,37 (3,71)	22	0,54	0,47
GOAL	5,98 (1,41)	8,70 (3,18)	22	0,61	0,44
GAP	3,76 (1,07)	1,64 (0,30)	22	3,63	0,07**
RANK	1,69 (0,05)	1,66 (0,03)	22	0,19	0,67

There is no difference between CF and healthy children.

Nevertheless, *p* for the QOL (Gap score) approached significance.

Items with best QOL VS worse QOL

	Children with CF		Healthy children	
	Item	M(SD)	Item	M(SD)
The 5 items with the best QOL (gap score)	Relation with mother	-0.21 (1.21)	Sport	0.33 (0.59)
	Relation with father	0.23 (0.62)	How my friends describe me	0.35 (1.59)
	Relation with grandparents	0.38 (0.96)	Clothes	0.49 (0.68)
	Leisure	0.80 (1.35)	Autonomy	0.60 (0.83)
	Relation with my friends	0.81 (1.51)	Leisure	0.61 (0.86)
The 5 items with the worse QOL (gap score)	Siblings	11.65 (27.17)	Siblings	6.14 (12.99)
	Health	7.70 (10.30)	Health	3.32 (4.17)
	Eating	7.63 (14.20)	Physical pain	2.93 (2.88)
	Frustration tolerance	5.40 (5.90)	Bedroom	2.79 (4.33)
	Autonomy	5.96 (8.92)	Sleep	2.48 (2.03)

For the **gap score**: a low mean suggest a better QOL

Results by items show a significant difference between the two groups for:

- **"autonomy"** (CF children: 5,96(8,92); healthy children : 0,60(0,83); F=4.30; p=0.05)
- "frustration tolerance" (CF children: 5,40(5,90); healthy children : 1,61(1,61); F=4.60; p=0.04)

4 DISCUSSION

Children with CF assess their health-related QOL (CF-specific module) in the same way that their overall QOL (generic module) and they have a **good overall QOL** as healthy children. However, we note that, clinically, children with CF have a worse QOL than the control group. This clinical difference can be explained by the fact that CF children have a lower present situation and higher expectations than healthy children. In this medical condition, we could think that children with CF have lower goal than healthy children. Results of comparison by items emphasize significant differences between CF children and healthy children for the "autonomy" and the "frustration tolerance". Analysis of the best and worse items among CF and healthy children has highlighted that a poor QOL is observed for "autonomy" in CF children in contrast to healthy children who have a good QOL in this life domain. Finally, the best QOL in CF children were based on **social support** unlike healthy children

5 CONCLUSION

These findings bring out the importance to have a **flexible tool** which allow to analyze both QOL for each life domains and overall QOL

This new tool suggests ways of intervention depending on child specific difficulties. His clinical originality is strengthened by the consideration of individual life plan taking into account the particular situation of children with CF.

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