

It's possible!  
to evaluate the emotional well-being of children  
and their parents attended in a pediatric palliative  
care unit.

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There is no conflict of interest in this study.

## Impact on psychological well-being

### CHILDREN

- Distress
- Worries
- Sadness.
- Fear (to be alone).
- Loss of control perception.
- Loss of independence
- Anxious symptoms
- Depressive symptoms

### PARENTS

- Feelings of ambivalence.
- Emotional alterations.
- Emotional claudication.
- Overprotection.
- Difficulties familiar communication.
- Separation anxiety.
- Loss of identity.
- Problems in couple relationships.
- Anticipatory grief

Moody K, Siegel L, Scharbach K, et al.: Pediatric palliative care. *Prim Care* 2011;38:327–361.

Kersun LS, Shemesh E: Depression and anxiety in children at the end of life. *Pediatr Clin North Am* 2007;54:691–708.

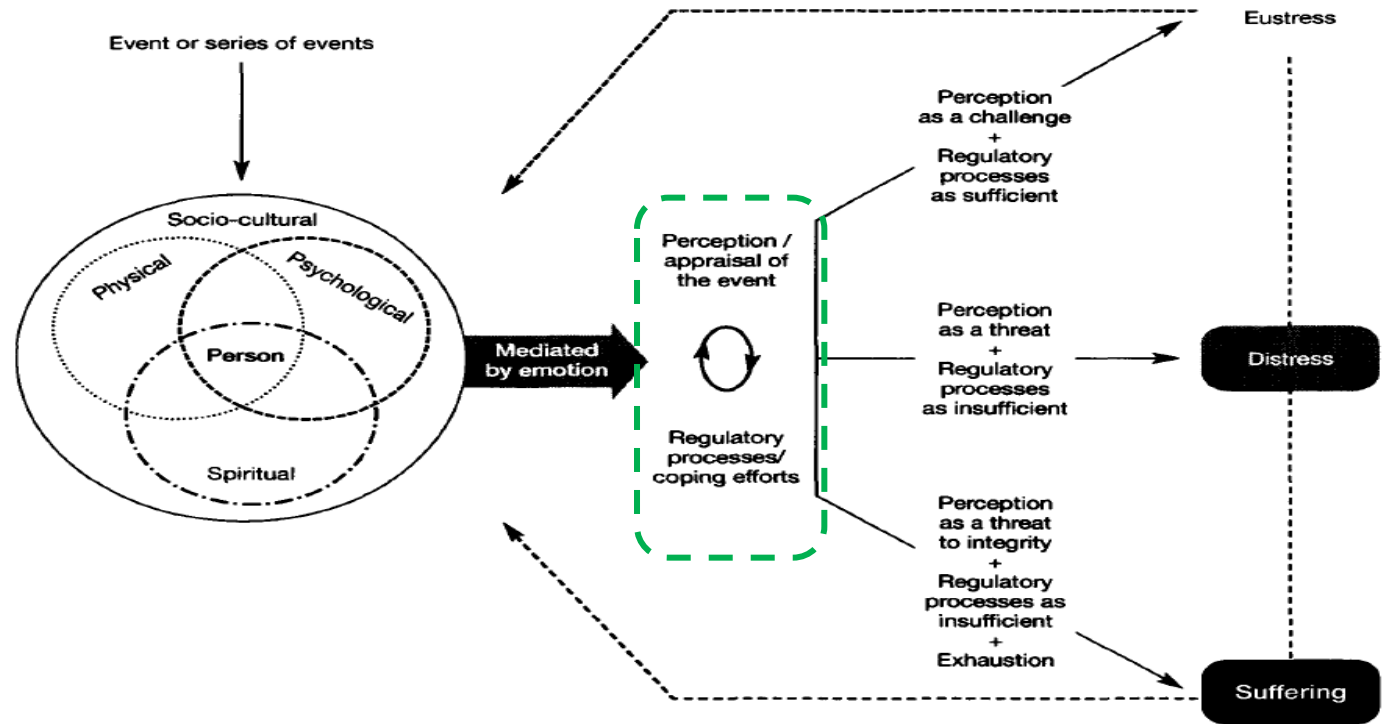
Keele L, Keenan HT, Sheetz J, Bratton SL: Differences in characteristics of dying children who receive and do not receive palliative care. *Pediatrics* 2013;132:72–78.

Krikorian A, Limonero JT. An integrated view of suffering in palliative care. *Journal of Palliative Care*. 2012; 28(1): p. 41-49.

**Impact on psychological well-being**

**Transactional model of stress**  
Lazarus & Folkman, 1984  
**An integrated view of suffering.**  
Krikorian, Limonero, 2012

**Figure 1 / An Integrated View of Suffering**



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## Impact on psychological well-being

### Transactional model of stress

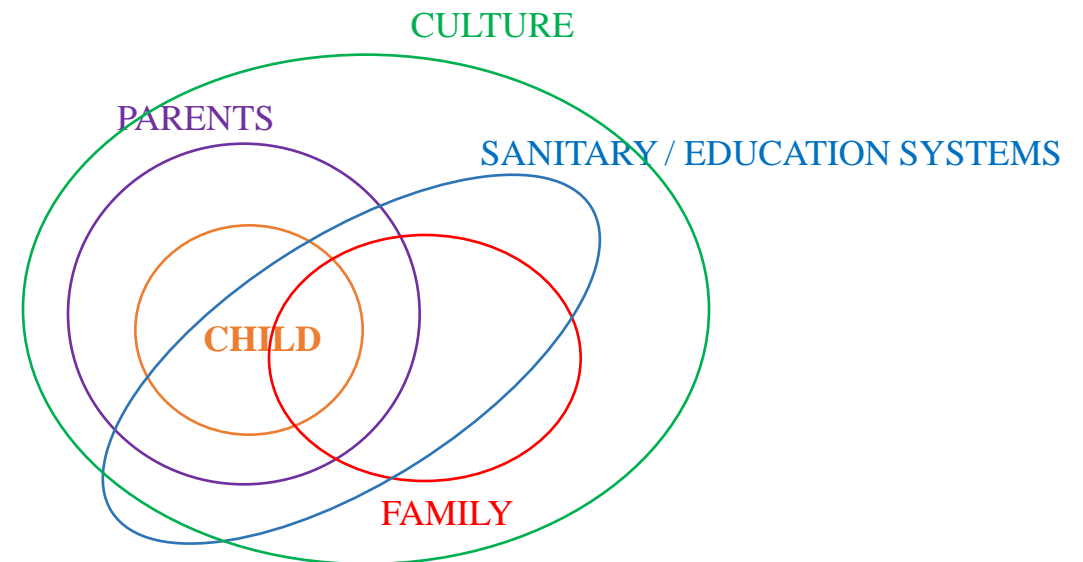
Lazarus & Folkman, 1984

### An integrated view of suffering.

Krikorian, Limonero, 2012

### Ecological systems theory.

Bronfenbrenner, 1992.



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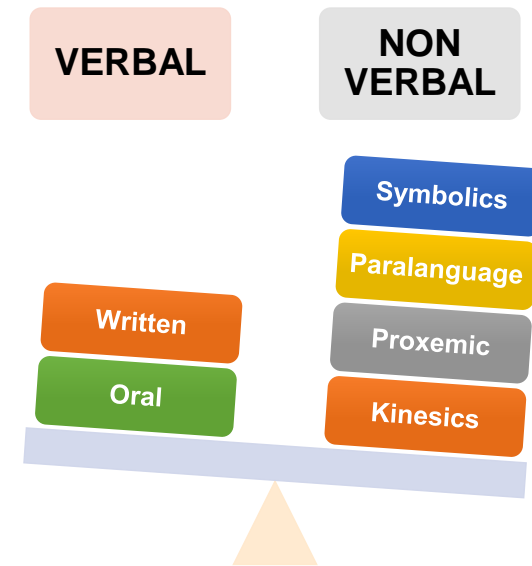
**Impact on psychological well-being**

**Transactional model of stress**  
Lazarus & Folkman, 1984  
**An integrated view of suffering.**  
Krikorian, Limonero, 2012

**Ecological systems theory.**  
Bronfenbrenner, 1992.

**Communication barriers**

**CHILD DEVELOPMENT**  
**COGNITIVE DETERIORATION**



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## AIMS

- Evaluate the emotional well-being of children and their parents when they are attended by a Paediatric Palliative Care Unit (PPCU).
- Know the differences in the evaluation of the emotional state of the child and their parents as evaluated by him or herself or by others.
- Describe the evaluation of the basic emotions and concerns of children at the end of life.
- Exploring differences in the evaluation of emotional well-being according to whether they are associated with sociodemographic or illness-related variables or not

## POPULATION

- Children attended by the specific Paediatric Palliative Care Unit of the Sant Joan de Déu Hospital of Barcelona from June 2017 to May 2018.
- Approved by the Clinical Research Ethics Committee of the Hospital.
- The selection of the sample was made by non-probabilistic sampling.

## DESIGNS

- It is a cross-sectional and descriptive study.

## STATISTIC ANALYSIS

- Descriptive multivariate analysis and of association between variables using the STATA 14.1 program.

# DATA COLLECTION



# DATA COLLECTION

## ABOUT CHILDREN

CHILDREN  
verbal communication

Spanish  
Questionnaire  
emotional distress  
(DME-R)

Thermometer of  
emotions

Associated  
thoughts

PARENTS &  
PROFESSIONALS

Analog visual  
scale  
(0 to 10)

External signs  
of emotional  
distress  
(DME-R)

## Clinical History:

Clinical and sociodemographic variables.

**CN2: Cuestionario para niños**  
Adaptado de Limonero, J. T., Mateo, D., Mate-Mendez, J., G. Evaluación de las propiedades psicométricas del cuestionario

NOMBRE NIÑO: \_\_\_\_\_  
Fecha: \_\_\_\_\_

1. ¿Cómo te encuentras de ánimo? ¿Bien, regular o mal? Entre 0 "muy mal" y 10 "muy bien", ¿qué puntuación le das?

0 1 2 3 4 5  
Muy Mal

2. ¿Hay algo que te preocupe? Si      No. En caso afirmativo, le preguntamos: En este momento, ¿qué es lo que más te preocupa?

Síntomas/Enfermedad  
 Familiares  
 Escuela  
 Amistades  
 Otros: \_\_\_\_\_

3. ¿Cómo llevas esta situación? Entre 0 "no me cuesta nada" y 10 "me cuesta mucho".

0 1 2 3 4 5  
No me cuesta nada

**Termómetro de las emociones y pensamientos**

10  
9  
8  
7  
6  
5  
4  
3  
2  
1  
0

6. HIJO/A

En los últimos días, ¿cómo valoras el bienestar de tu hijo/a?

0 1 2 3 4 5 6 7 8 9 10  
Muy malo Muy bueno

**SIGNOS EXTERNOS DE MALESTAR**

¿Qué observas para evaluarlo de esta forma?

Expresión facial. (tristeza, miedo, euforia, enfado, ...)  
 Alteraciones conductuales. (irritabilidad, agresividad, conductas regresivas, miedos no habituales...)  
 Disminución de la necesidad de interacción / aislamiento. (mutismo, rechazo visitas, ausencia distracciones, incommunicación, ...)  
 Demanda constante de atención / compañía. (quejas constantes, ...)  
 Alteraciones del comportamiento nocturno. (insomnio, pesadillas, quejas, ...)  
 Otros: \_\_\_\_\_

Wiener L, Battles H, Zadeh S, Widemann BC, Pao M. Validity, specificity, feasibility and acceptability of a brief pediatric distress thermometer in outpatient clinics. *Psycho-oncology*. 2017; 26(4): p. 461-468.

Limonero JT, Mate J, Mateo D, Gonzalez-Barboteo J, Bayes R, Bernaus M, et al. Desarrollo de la escala DME-C: una escala para la detección del malestar emocional de los cuidadores principales de personas con enfermedad avanzada o al final de la vida. *Ansiedad y Estrés*. 2016 Julio-Diciembre; 22(2): p. 104-109.

Limonero JT, Mateo D, Mate-Mendez J, Gonzalez-Barboteo J, Bayes R, Bernaus M, et al. Evaluación de las propiedades psicométricas del cuestionario de Detección de Malestar Emocional (DME) en pacientes oncológicos. *Gaceta Sanitaria*. 2012; 26(2): p. 145-152.

# DATA COLLECTION

ABOUT PARENTS

PARENTS

Spanish  
Questionnaire  
emotional distress  
Caregivers  
(DME-C)

Brief Resilient  
Coping Scale  
(BRCS)

CHILDREN  
Verbal communication

Analog visual  
scale  
(0 to 10)

PROFESSIONALS

Analog visual  
scale  
(0 to 10)

External signs of  
emotional distress  
(DME-C)

## Clinical History:

Clinical and sociodemographic variables.

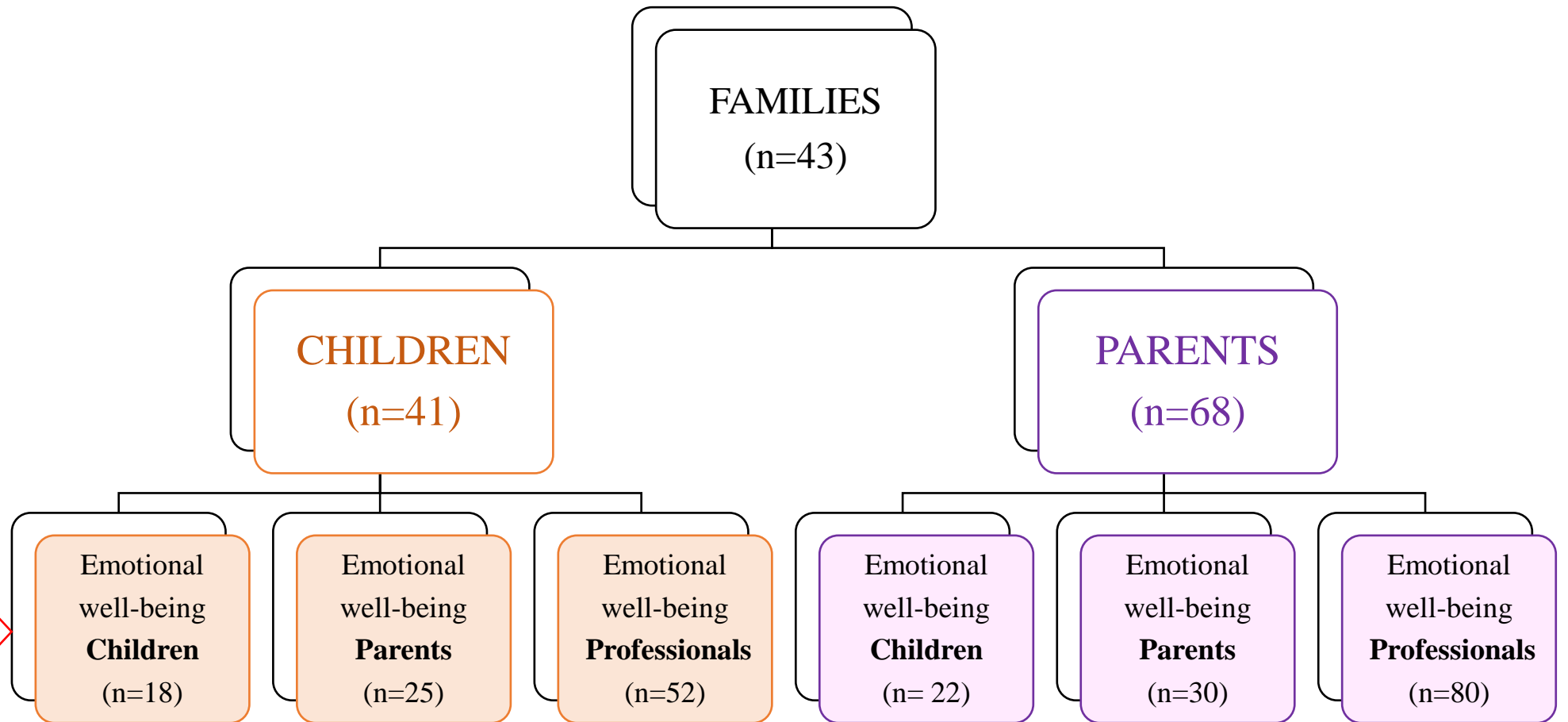
The collage includes several forms:

- CP: Cuestionario para padres.** A form for parents with fields for child name, date of birth, and parent information. It includes a question: "¿Cómo se encuentra de ánimos?" with a 0-10 analog scale and radio button options for Bien, Mal, and Regular.
- 2. En los últimos días, ¿cómo crees que se encuentra este padre/madre/tutor?** A form with a 0-10 analog scale and radio button options for Bien, Mal, and Regular.
- PADRE 1:** A form asking "En los últimos días, ¿cómo crees que se encuentra este padre/madre/tutor?" with a 0-10 analog scale and radio button options for Bien, Mal, and Regular.
- PADRE 2:** A form asking "En los últimos días, ¿cómo crees que se encuentra este padre/madre/tutor?" with a 0-10 analog scale and radio button options for Bien, Mal, and Regular.
- SIGNOS EXTERNOS:** A form asking "¿Qué observas para evaluarlo de esta forma?" with two columns of radio button options for signs of distress (e.g., llanto, miedo, desbordamiento, irritabilidad, rechazo de contacto, dificultades de información).

Limonero JT, Mate J, Mateo D, Gonzalez-Barboteo J, Bayes R, Bernaus M, et al. Desarrollo de la escala DME-C: una escala para la detección del malestar emocional de los cuidadores principales de personas con enfermedad avanzada o al final de la vida. *Ansiedad y Estrés*. 2016 Julio-Diciembre; 22(2): p. 104-109.

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# SAMPLE

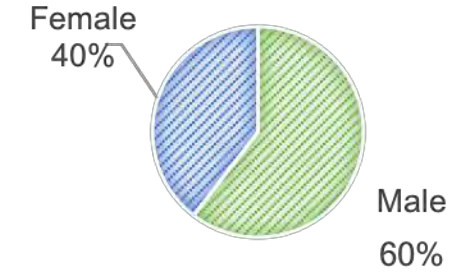


**227 assesments**  
95 children  
132 parents

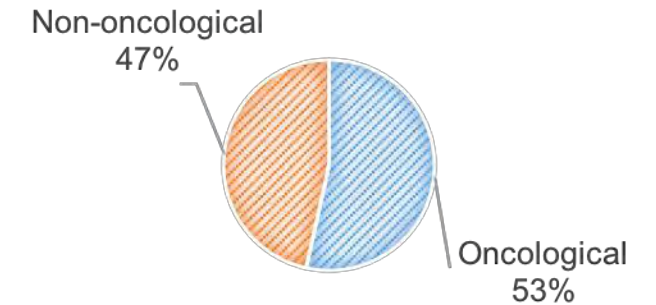
# RESULTS

<i>Characteristics of the sample (n=43)</i>		
<i>Sociodemographic</i>	<b>Age children (years)</b>	M=11.00 (DT=5.89); Md=10.31; R=0.14-20.79
	<b>Gender children</b>	Male= 26(60.47%) Female=17 (39.53%)
	<b>Family coexistence</b>	Couple-parents=32 (74.42%) Separated parents=8 (18.60%) Single parent=3(6.98%)
	<b>Siblings</b>	Yes=36(83.72%)
	<b>Origin child</b>	Spain=29 (67.44%) Latin-American=8 (18.60%) Africa=4(9.30%) Europe=2(4.65%)
	<b>Origin parents</b>	Spain=25 (58.14%) Latin-American=10 (23.26%) Africa=6(13.95%) Europe=2(4.65%)
	<b>Place of residence</b>	Barcelona=37(86.05%) Rest of Catalonia=5(11.62%) Rest of Spain=1(2.33%)
	<b>School attendance</b>	No=25(59.52%) Yes=17(40.48%)
<i>Disease</i>	<b>Kind of disease</b>	Onco-hematological= 23 (53.49%) Non-oncohematological=20 (46.51%)
	<b>Communication capacity</b>	Verbal=19(44.19%), Only Non-verbal=24(55.81%)
	<b>Clinical situation</b>	Stability=29(67.44%) Progression=14(32.56%)

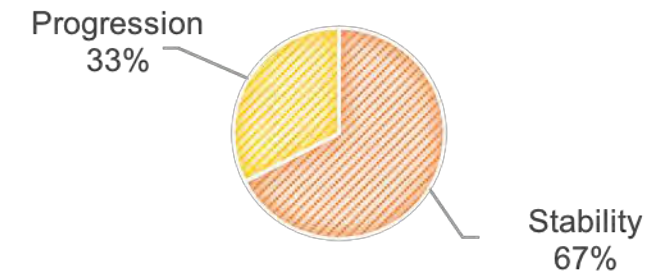
**GENDER CHILD**



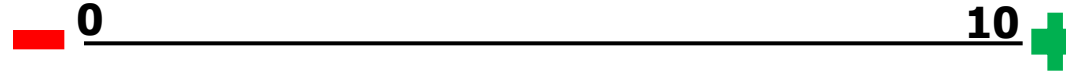
**DISEASE**



**CLINICAL SITUATION**



# VALUE of EMOTIONAL WELL-BEING



	Evaluations CHILDREN (n=89)					Evaluations PARENTS (n=118)					
	n	M	SD	Min	Max	n	M	SD	Min	Max	
<i>Children</i>	14	7.75	1.66	4.50	10	<i>Children</i>	18	6.42	2.23	4.00	10
<i>Parents</i>	24	6.86	1.46	4.00	10	<i>Parents</i>	29	5.61	1.95	0.00	9.00
<i>Professionals</i>	51	6.25	1.54	3.00	9.00	<i>Professionals</i>	71	5.62	1.79	1.00	8.00

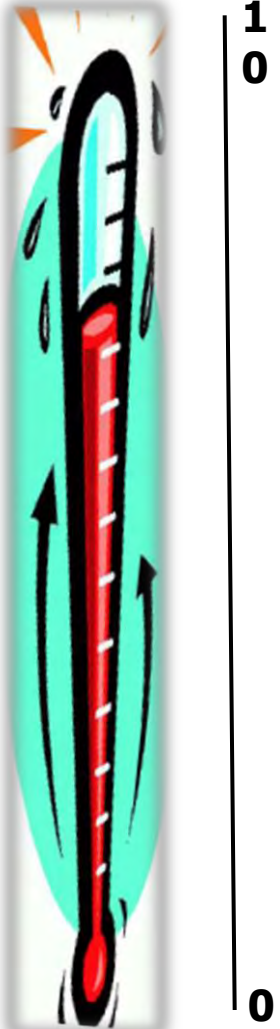
*Children and Professionals:  
Statistically significant differences (p=0.002)*

*Non Statistically significant differences (p=0.27)*

*Not statistically significant differences depending on the child's illness.*

# CHILDREN: EMOTIONS AND WORRIES

*Very much feel*



	<b>n</b>	<b>M</b>	<b>SD</b>	<b>Rank</b>	<b>Associated Thoughts</b>
<b>Principal worry</b>	15				Disease=80.00%
<b>Happiness</b>	14	8.50	2.07	4 - 10	Friendships=42.86% Family=35.74% School=7.14% Disease=7.14% Others=7.14%
<b>Sadness</b>	14	2.89	2.83	0 - 8	Disease=54.54% Family=27.27% School=9.09% Others=9.09%
<b>Anger</b>	14	4.86	3.42	0 - 10	Disease=41.66% Family=33.33% Friendships=16.67% Others=8.33%
<b>Fear</b>	14	4.17	3.14	0 - 10	Disease=50.00% Others=50.00%
<b>Nervousness</b>	7	3.08	2.81	0 - 6.5	Disease=40.00% Others=20.00% School=20.00% Friendships=20.00%

*Not feel*



# CHILDREN: EXTERNAL SIGNS OF EMOTIONAL DISTRESS

“Positive words”

Table. Emotional signs of emotional distress of children.

	n	M	SD	Rank	Emotional signs
Parents	23	2.13	1	4	Facial Expression = 73.91% Behavioural Alterations = 43.48% Decrease Interaction = 39.13% Others = 30.43% Demand Attention = 13.04% Nocturnal Alterations = 8.70%
Professionals	51	2.51	0.99	1-5	Facial Expression = 74.51% Behavioural Alterations = 64.71% Decrease Interaction = 35.29% Others = 33.33% Demand Attention = 29.41% Nocturnal Alterations = 17.65%

## EXTERNAL SIGNS when NOT VERBAL COMMUNICATION

	Parents	Professionals	p (Fisher's exact)
	n (%)	n (%)	
Facial expression	16 (80%)	20 (68.97%)	0.516
Behavioural alterations	9 (45.00%)	23 (79.31%)	0.035
Decrease Interaction	8(40.00%)	8 (27.59%)	0.362
Demand Attention	3 (15.00%)	13 (44.83%)	0.035
Nocturnal alterations	2 (10.00%)	7 (24.14%)	0.277
Others	4 (20.00%)	13 (26.53%)	0.516

Behavioural alterations.  
(irritability, aggressiveness,  
regressive behaviours,  
unusual fears ...)

Constant demand for  
attention / company.  
(constant complaints, ...)

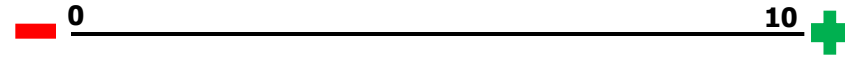
# PARENTS

Table . *Emotional well-being of parents*

	n	M	SD	Rank	Description
<b>Principal worries</b>	28	8.36/10	2.36	0 - 10	Disease=67.86% Family=28.57% Others=3.56%
<b>Resilience (BRCS)</b>	18	13.58/20	3.61	6.5-19	BRCS<13: lower resilience BRCS>17: higher resilience
<b>DME-C</b>	28	8.88/20	3.94	2-20	DME-C>11: emotional distress
<b>External Signs Professionals (DME-C)</b>	77	2.25	1.22	0-5	Visible emotional lability = 74.03% Difficulties information = 66.67% Rejection Socialization = 40.26% Separate child = 35.06% Signs angry = 22.08% Professional rejection = 10.39% Others = 26.67%

# SOCIO-DEMOGRAPHIC and ILLNESS VARIABLES

# CHILDREN



		Emotional well-being children				Emotional well-being parents			
		n	M	SD	p	n	M	SD	p
<b>Clinical Situation</b>	Stability	10	<b>8.35</b>	1.20	0.03	13	<b>6.96</b>	2.35	0.10
	Progression	4	<b>6.25</b>	1.85		5	<b>5.00</b>	1.06	
<b>School attendance</b>	Yes	4	<b>7.50</b>	1.61	0.74	7	<b>4.57</b>	0.53	0.001
	No	10	<b>7.85</b>	2.00		11	<b>7.59</b>	2.10	
<b>Gender</b>	Male	10	<b>7.65</b>	1.56	0.48	8	<b>6.69</b>	2.19	0.39
	Female	4	<b>8.00</b>	2.12		9	<b>5.78</b>	2.06	
<b>Origin child</b>	Spain	10	<b>7.92</b>	1.44	0.55				
	Others	4	<b>7.31</b>	2.30					
<b>Origin parents</b>	Spain	10	<b>7.92</b>	1.44	0.55	13	<b>6.42</b>	2.23	0.99
	Others	4	<b>7.31</b>	2.30		5	<b>6.40</b>	2.51	
<b>Place of residence</b>	Barcelona	12	<b>7.94</b>	1.73	0.32	16	<b>6.09</b>	2.12	0.10
	Others	2	<b>6.62</b>	0.18		2	<b>9.00</b>	1.41	
<b>Family coexistence</b>	Couple-parents	11	<b>7.75</b>	1.76	1.00	16	<b>6.09</b>	2.12	0.10
	Others	3	<b>7.75</b>	1.52		2	<b>9.00</b>	1.41	

# PARENTS



		Emotional well-being children				Emotional well-being parents			
		n	M	SD	p	n	M	SD	p
<b>Clinical Situation</b>	Stability	18	<b>6.97</b>	1.27	0.59	19	<b>5.86</b>	1.82	0.37
	Progression	6	<b>6.58</b>	2.11		10	<b>5.15</b>	2.21	
<b>School attendance</b>	Yes	14	<b>6.82</b>	1.41	0.84	15	<b>5.75</b>	2.17	0.70
	No	10	<b>6.95</b>	1.64		14	<b>5.46</b>	1.76	
<b>Gender</b>	Male	16	<b>7.12</b>	1.31	0.25	3	<b>5.33</b>	1.04	0.96
	Female	8	<b>6.38</b>	1.75		16	<b>5.39</b>	1.72	
<b>Siblings</b>	Yes	17	<b>7.00</b>	1.16	0.53	22	<b>5.81</b>	1.91	0.35
	No	7	<b>6.57</b>	2.15		7	<b>5.00</b>	2.11	
<b>Origin child</b>	Spain	18	<b>6.94</b>	1.59	0.70				
	Others	6	<b>6.67</b>	1.17					
<b>Origin parents</b>	Spain	15	<b>6.87</b>	1.55	0.97	19	<b>5.28</b>	1.95	0.21
	Others	9	<b>6.89</b>	1.43		10	<b>6.25</b>	1.89	
<b>Family coexistence</b>	Couple-parents	19	<b>6.92</b>	1.57	0.77	56	<b>5.82</b>	1.78	0.42
	Others	5	<b>6.70</b>	1.20		15	<b>4.60</b>	2.63	



# PROFESSIONALS



		Emotional well-being children				Emotional well-being parents			
		n	M	SD	p	n	M	SD	p
<b>Clinical Situation</b>	Stability	33	<b>6.48</b>	1.46	0.15	44	<b>6.07</b>	1.56	0.01
	Progression	18	<b>5.83</b>	1.63		27	<b>4.89</b>	1.93	
<b>School attendance</b>	Yes	20	<b>5.95</b>	1.61	0.41	28	<b>5.20</b>	1.90	0.17
	No	29	<b>6.31</b>	1.42		40	<b>5.81</b>	1.71	
<b>Gender</b>	Male	29	<b>6.05</b>	1.44	0.28	24	<b>5.50</b>	1.72	0.69
	Female	22	<b>6.52</b>	1.65		47	<b>5.68</b>	1.85	
<b>Siblings</b>	Yes	41	<b>6.32</b>	1.64	0.56	57	<b>5.56</b>	1.88	0.58
	No	10	<b>6.00</b>	1.05		14	<b>5.86</b>	1.41	
<b>Origin child</b>	Spain	41	<b>6.37</b>	1.38	0.30				
	Others	10	<b>5.80</b>	2.10					
<b>Origin parents</b>	Spain	36	<b>6.33</b>	1.44	0.58	53	<b>5.45</b>	1.84	0.18
	Others	15	<b>6.07</b>	1.79		18	<b>6.11</b>	1.60	
<b>Place of residence</b>	Barcelona	45	<b>6.11</b>	1.54	0.07	64	<b>5.52</b>	1.82	0.14
	Others	6	<b>7.33</b>	1.03		7	<b>6.57</b>	1.27	
<b>Family coexistence</b>	Couple-parents	40	<b>6.34</b>	1.62	0.47	56	<b>5.85</b>	1.69	0.04
	Others	11	<b>5.95</b>	1.19		15	<b>4.77</b>	1.97	

# CONCLUSIONS

# CONCLUSIONS

- It is possible to **assess** emotional well-being with children and their families
- Children at the end of life have all the basic emotions, including **happiness** and they talk about the **illness**
- There is a tendency to evaluate the emotional well-being more positively by the **protagonists**
- The **communicative capacity** and **clinical situation** of the child are variables to consider when evaluating emotional well-being

# CONCLUSIONS

- External signs of well-being and **"positive words"** are important to establish a "shared language" with parents
- Parents get good scores regarding resilience and emotional distress by comparing it to adult caregivers
- Further studies are needed to explore the relationship with the sociodemographic variables

# LIMITATIONS

- Non-homogenous sample with respect to the **parents** (between oncological and non-oncological illness)
- They are cross sections, not **longitudinal**
- The evaluation tools are **not validated** in our population

# FUTURE LINES

- Establish **specific evaluation tools** (PhD in PPC)
- Study of the relationship of **sociodemographic variables and of illness** in emotional well-being
- Explore the **qualitative** methodology

# THANKS

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