

Development and validity of an instrument for assessing the family subsystems of pediatric patients hospitalized due to chronic illness (eSisFam)

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Original article

ABSTRACT

Background

According to the family systems model, the family consists of three main subsystems: marital, parental, and filial, all of which perform specific functions. A chronic pediatric illness presents challenges to these subsystems, leading family members to make the necessary adjustments in order to maintain system balance. The evaluation of families in a public hospital setting is hampered by time constraints and limited human resources to carry out a precise evaluation.

Objective

The aim of this study was to develop and validate a practical instrument for the evaluation of family subsystems during the hospitalization of a pediatric patient with a chronic illness (eSisFam).

Method

Based on a review of scientific literature and well-known family functioning instruments, a new measure with four sections was developed: the general system and the marital, parental, and filial subsystems. This was applied to 312 primary caregivers of chronically ill hospitalized pediatric patients in a public pediatric hospital. Likert-type items with four response options were self-administered with a computer program. Content validity, construct validity, and reliability were assessed.

Results

Content validity was obtained by 80% interjudge agreement. Construct validity was evaluated by exploratory factor analysis, resulting in three factors for the general system (cohesion, communication, and adaptation); two for the marital subsystem (affective-sexual relationship and distancing-infidelity); three for the parental subsystem (wellbeing, shared responsibility, and care of siblings), and three for the filial subsystem (wellbeing, knowledge of the illness, and acceptance-participation). We assessed the internal consistency with Cronbach's alpha coefficients; these were higher than 0.80 in all subscales.

Discussion and conclusion

The instrument (eSisfam) that was developed is a valid and reliable measure to assess the general functioning of the family system and the marital, parental, and filial subsystems. This measure could be used in pediatric hospitals for the early detection of family situations that might interfere with child or adolescent medical attention.

Key words: Family assessment, family subsystems, pediatric chronic illness.

RESUMEN

Antecedentes

La teoría sistémica de la familia plantea que en ésta existen tres subsistemas: conyugal, parental y filial, los cuales responden, según su particular función, cuando uno de los miembros en edad pediátrica enfrenta alguna enfermedad crónica que amenaza su vida. La evaluación de las familias en un contexto hospitalario institucional presenta distintos desafíos debido al tiempo mínimo necesario para obtener un diagnóstico preciso y por la escasez de recursos humanos preparados para dichas tareas.

Objetivo

Desarrollar y validar un instrumento para la evaluación de los subsistemas familiares durante la hospitalización a causa de una enfermedad crónica pediátrica (eSisFam).

Método

A partir de la bibliografía y de instrumentos conocidos de funcionamiento familiar, se conformó uno nuevo de cuatro secciones: sistema general y subsistemas conyugal, parental y filial. Participaron 312 cuidadores primarios de pacientes crónicos internados en un hospital público pediátrico. Los reactivos tipo Likert con cuatro opciones de respuesta, fueron contestados en un programa de cómputo. Se determinó la validez de contenido, de constructo y la confiabilidad.

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Received first version: July 4, 2013. Second version: July 21, 2014. Accepted: September 19, 2014.

Resultados

La validez de contenido arrojó más del 80% de acuerdo interjueces. La validez de constructo por análisis factorial exploratorio identificó tres causas del sistema general (cohesión, comunicación y adaptación), dos del subsistema conyugal (relación afectivo-sexual y distanciamiento-infidelidad), tres del parental (bienestar, responsabilidad compartida y cuidado de los hermanos) y tres del filial (bienestar, conocimiento de la enfermedad y aceptación-participación) con coeficientes alfa de Cronbach superiores a 0.80.

Discusión y conclusión

El instrumento desarrollado (eSisFam) es válido y confiable para una evaluación general del sistema familiar y de los subsistemas conyugal, parental y filial. La medida podrá ser utilizada en el hospital de pediatría para la detección temprana de situaciones familiares que pudieran interferir con la atención médica del niño o adolescente.

Palabras clave: Evaluación familiar, subsistemas familiares, enfermedad crónica pediátrica.

BACKGROUND

As the basic system of an individual's growth and wellbeing, the family is the primary source of support when the health of one of its members is affected.¹⁻³ In the context of chronic illness, the family suffers and becomes ill together with the patient,^{4,5} as what happens to one family member affects the others in different ways and the subsystems that form it,^{6,7} as well as its functioning and dynamic.^{8,9} As such, the family group assumes changes to adapt itself to the demands of the new situation, but at the same time it continues meeting its bio-psychosocial functions. The family participates more actively in the process of illness and treatment when it affects children rather than adults.¹⁰ For this reason, what affects the family can be even greater, and having a child in hospital or with a life-threatening illness is particularly distressing for parents and siblings.¹¹⁻¹⁶

Pelechano¹⁷ states that when facing an illness, a family must reconstruct itself in terms of activities and roles; changes that are not always accepted. On the other hand, according to Lanzarote and Torrado,¹⁸ an early assessment of the family may help to determine the difficulties and establish what is fundamental in evaluating adaptation, cohesion, and communication, among other aspects.

Generally during the process of medical treatment, interest is focused on the patient and their condition, and it is rare that family factors involved in the process are taken into account.¹⁷ The assessment of families in an institutional hospital context presents various challenges, among which are the limited time available to obtain a precise diagnosis, the lack of practical and effective instruments for diagnosis, and the lack of human resources able to carry out these tasks.

Upon revising the known instruments for measuring family functioning,¹⁹⁻²⁵ it was found that in general they were not made for people in families where chronic conditions are present. Because of this, the drafting of the questions and the instructions did not assess changes in the family due to situations specific to illness. None of them made a joint assessment of the marital (the relationship between the primary carer and their partner), parental (parental figures towards the illness), or filial (the patient's siblings towards the illness) subsystems in the family. The Scale of family functioning facing a chronic illness (*Escala de Funcionamiento Familiar ante una Enfermedad Crónica*), developed in 2007 by Alvarado, Barrios, and Montero, cited by Montero,²⁶ although adequate for assessing families with a chronic illness, was validated in adult patients and does not focus on the family subsystems, nor on their particular problems or treatment needs.

Table 1. Characteristics of the participating families

	N	%		N	%
<i>Patient's Age</i>			<i>Family's home state</i>		
Preschool	76	24	Mexico City or Mexico State	412	45
School-age	109	35	Other State in Mexico	170	55
Adolescent	127	41			
<i>Primary carer's relationship to the patient</i>			<i>Patient's Number of Siblings</i>		
Mother	271	87	None	46	15
Father	26	8	One	130	42
Maternal grandmother	7	2	Two	99	32
Other (cousins, uncles/aunts, parents-in-law, stepmom, etc)	8	3	Three or more	37	11
<i>Type of family</i>			<i>Patient's type of illness</i>		
Nuclear, two parents	174	56	Oncological or hematological*	105	34
Extended, two parents	49	16	Neurological or neurosurgery	68	22
Nuclear, one parent	42	13	Nephrological or urological	39	12
Extended, one parent	40	13	Other (rheumatology, infectology, pulmonology, cardiology, maxillo-facial, etc.)	69	22
<i>Compound</i>	7	2			

*Including leukemia and other hematological conditions.

For this reason, the aim of the present study was to develop an instrument to measure family functioning in a general system and in the marital, parental, and filial subsystems. Each section evaluates relevant aspects in the current stage of the chronic pediatric illness during their hospitalization. The instrument was applied to primary carers through a computer program that allowed a fast and adequate application and scoring of the responses.

METHOD

The study was carried out in the Pediatric Hospital of the 21st Century National Medical Center of the Mexican Social Security Institute (IMSS) and it was approved by that organization's ethics and research Committee.

Table 2. General System. Three factors were extracted with eigen values of 1 or greater

Items on the General System	Factors		
	1	2	3
At this stage of the illness, in our family...*			
G54...we support each other while the patient is in hospital	.809		
G55...we make joint decisions for important matters of the illness	.726		
G37...there is a union to confront the illness	.707		
G44...we support the person who takes care of the patient the most	.698		
G53...when someone has a problem, the others try to help them	.695		
G52...we meet the needs of the patient in agreement	.691		
G47...when a problem comes up with the illness, we suggest solutions	.669		
G49...we are organized for visiting the patient in hospital	.661		
G2 ...we have the support of our family members	.661		
G20...each member takes on the responsibility that applies to them	.659		
G46...although we might not be there, we are still interested in the patient's situation	.641		
G10...we plan activities to meet the needs of the family	.637		
G60...it is important to stick together right now	.592		
G7 ...things are generally happy despite the illness	.584		
G33...we plan activities to meet the needs of the patient	.584		
G19...the primary carer stays in touch with other family members	.575		
G48...it is important for us to keep informed about the illness	.559		
G27...the needs of the primary carer are important to us as well	.544		
G42...we talk about the patient's needs	.538		
G29...we think that the patient is everyone's responsibility	.478		
G8 ...we talk about how we feel about the illness		.690	
G31...we talk openly about what is happening to us		.666	
G13...we can talk to each other about how sad we feel		.650	
G30...we are allowed to cry when we feel sad about the patient		.632	
G22...we are not afraid to talk about the illness and the treatment		.621	
G35...we talk about what might happen to the patient in the future		.614	
G16...we can express our sadness by crying		.592	
G4 ...we can talk openly about what we think about the illness		.482	
G3 ...we show both positive and negative feelings		.470	
G12...when someone feels angry about the patient's situation, they can express it		.402	
G40...we are "on another planet"			.727
G45...it has been difficult for us to do different or new things because of the illness			.642
G18...it has been difficult for us to accept what is happening			.614
G43...it is difficult to agree about the illness			.598
G28...we find it hard to change our habits or routines			.531
G23...it is difficult to follow hospital rules			.520
G50...we try to live life as normally as possible			.491
G62...it has been difficult to stop doing things we did before			.489
G41...in spite of the difficult situation, we give ourselves time for fun			.462
G36...we fight or argue because of this situation			.445
G59...we can talk about the illness without fighting, despairing, or crying			.413
G24...we have been able to organize our home around the illness			.410

*This phrase appears in each of the items on the general system.

Table 3. Marital Subsystem. Two factors were extracted with Eigen values of 1 or greater

Items of the Marital Subsystem	Factors	
	1	2
At this stage of the illness, as a couple...*		
C19...we are interested in our sexual relationship	.809	
C14...we can be sexually satisfied	.787	
C18...we try to devote time to each other	.780	
C5 ...we try to conserve our intimate space	.762	
C8 ...we can mutually enjoy ourselves at this time	.758	
C9 ...we show the love we feel towards each other	.716	
C24...we can feel passionate towards each other	.707	
C3 ...our sexuality is important	.679	
C31...we show sexual interest in each other	.667	
C32...we are attractive to each other	.661	
C1 ...we have time to spend together	.624	
C21...we have time to go out alone	.593	
C4 ...we understand how the other feels	.587	
C7 ...we avoid the subject of our sexuality	.514	
C22...the quality of our sexual relations has gone down	.470	
C28...we have reduced our sexual relations	.468	
C29...we feel guilty for enjoying our sexual relationship	.400	
C23...we have been at the point of divorce because of the illness		.702
C34...we have been interested in other people		.690
C17...there has been infidelity		.666
C30...one of us says the illness is a pretext to deceive the other		.660
C20...we have emotionally distanced ourselves from one another		.602
C6 ...the illness caused our separation		.572
C33...if one is unfaithful, they think the other is, too		.556
C12...we have shown sexual interest in other people		.543
C15...one of us feels displaced by the patient		.494
C25...we are distant because one is at the hospital and the other is working		.415

*This phrase appears in each of the items of the marital subsystem.

Obtaining the questions

Questions were formulated for each section based on the information reported in the bibliography. To assess the general system, certain questions were modified that measured cohesion, communication, and adaptation of the following Scales: Family Environment Scale (FES) by Moss, Moss, and Trickette,²¹ Family Functioning (FFSIL) by De la Cuesta, Pérez, Louro, and Bayarre,²⁷ and Family Functioning when Facing an Illness (EFFE) by Montero.²⁶ Questions were chosen that could be applied in the context of chronic pediatric illnesses.

Instrument

The instrument was made up of questions which were organized into four sections: one related to the general system, and three on the marital, parental, and filial subsystems. The general system assessed the dimensions of cohesion, communication, and adaptation of the family in general. The section for the marital subsystem assessed affective-sexual and distancing-infidelity dimensions between the primary carer and their partner. The section which assessed the

parental subsystem consisted of questions which measured the dimensions of shared responsibility between the parental figures for treating the illness, their wellbeing, and care of the patient's siblings. Finally, the section dedicated to the filial subsystem assessed siblings' knowledge about the condition, their wellbeing, and their participation in needs arising while their sibling was in treatment.

The Likert-type instrument had four response options (always, almost always, sometimes, never). They were applied individually to the primary carer, who responded using a specially-designed computer program that was easy to respond to regardless of level of education and computer knowledge.

Each section had specific instructions and an example, with the aim of the person taking into account all members that made up that subsystem, and giving a response that represented it as a whole.

It is important to indicate that the instrument adapts to families who did not have any subsystem. Each section can be applied and scored separately from the others, and as such, it is possible to obtain an individual evaluation for each one, given that not all families are made up of the four sections assessed.

Table 4. Parental Subsystem. Three factors were extracted with Eigen values of 1 or greater

Items on the Parental Subsystem	Factors		
	1	2	3
At this stage of the illness, as parents...*			
P41...we are depressed	.788		
P47...we are desperate	.786		
P32...we feel frustrated by the illness	.721		
P39...we are downhearted by the situation with our child	.715		
P43...we are anxious	.683		
P45...we are worried	.671		
P3 ...we have had problems sleeping	.650		
P28...we feel we are to blame for our child's illness	.617		
P6 ...we have disregarded our own health because of caring for the patient	.610		
P34...we have suffered headaches, stomach pains, body pains, or other discomfort	.594		
P35...this difficult situation makes us angry	.585		
P37...we feel powerless against our child's illness	.576		
P48...one or both of us has become ill because of this situation	.570		
P9 ...our eating habits have changed	.562		
P50...one or both of us is tired or worn out by this situation	.530		
P14...we have frequently been sick	.430		
P19...we are both aware of the patient and their condition		.793	
P1 ...we share responsibility of the illness		.787	
P25...we give each other moral support		.763	
P7 ...we both feel responsible for our home		.754	
P30...although one is absent from the hospital, they stay abreast of the situation		.752	
P27...we support each other in decisions about medical procedures		.749	
P13...we organize home activities by mutual agreement		.682	
P24...we support each other financially		.675	
P15...we support each other with housework		.640	
P21...we are on the lookout for medical signs		.526	
P18...one of us carries the load of this situation more than the other		.524	
P23...we are informed of what happens with the patient in hospital		.519	
P53...we understand the moods of our healthy children			.823
P42...we listen to our other children when they want to talk			.762
P20...we meet the needs of our other children			.716
P51...we know how our children feel about their sick sibling			.715
P40...we take the other children's opinions into account			.665
P44...we show affection toward our other children			.657
P33...we believe we pay enough attention to the other children			.505

*This phrase appears in each of the items on the parental subsystem.

Procedures for content validity

Expert interjudge agreement. Ten expert judges in mental health participated: five clinical psychologists and five peditopsychiatrists. They were asked to assess the questions listed by subsystems, as well as their dimensions on a computer program. They were also asked to indicate whether or not the questions belonged to the operational definition (which they were given on a printed sheet) and the dimension indicated, according to their professional criteria and clinical experience.

Agreement between primary carers. Some 12 primary carers of patients in the pediatric hospital participated (eight mothers, two fathers, and two grandmothers). Individually, they read the questions for each subsystem on the computer and advised if these and the instructions were clear, un-

derstandable, difficult to answer, and whether or not they applied to their own situation. They were also asked to give any comments or suggestions which would improve the questions.

Procedure for construct validity

The first step was to request the voluntary participation of 312 primary carers of pediatric patients hospitalized with chronic illnesses at preschool, school, and adolescent age in a third treatment level hospital. Those who agreed to participate signed an informed consent letter. The primary carer could be the mother, father, or other family member or known person who was with the patient in hospital most of the time. The application of the 210 initial questions was done using portable computers.

Translation of the original version published in spanish in: Salud Mental 2015, Vol. 38 Issue No. 4.

Table 5. Filial Subsystem. Three factors were extracted with Eigen values of 1 or greater

Items on the Filial Subsystem	Factors		
	1	2	3
At this stage of the illness, the patient's siblings...*			
F38...have become fearful	.725		
F36...have been downhearted	.711		
F37...have had problems with their eating habits	.706		
F40...have felt alone because their parents are in hospital	.672		
F18...have suffered headaches, stomach pains, body pains, or other discomfort	.647		
F17...have been angry about their sibling's situation	.611		
F20...have had insomnia, nightmares, or other sleep problems	.611		
F3 ...have had sudden mood changes	.602		
F14...ask as a complaint: "why does my sibling have this illness?"	.568		
F52...have had some of their activities affected because of the illness	.562		
F24...have found it difficult to stay in someone else's care	.527		
F8 ...have had behavioral problems	.516		
F15...have had lower grades at school	.509		
F6 ...have frequently been sick	.509		
F34...have expressed loneliness because their sibling is not around	.509		
F30...are afraid of getting ill like their sibling	.500		
F54...have expressed feeling guilty for being healthy themselves	.472		
F46...have isolated themselves from others	.463		
F22...have felt to blame for their sibling's illness	.429		
F31 ...have correct information about the illness		.803	
F21...have clear information about the illness		.796	
F25...have had the treatment explained to them in a way they will understand		.767	
F19...know what the illness consists of		.740	
F1 ...have knowledge about their sibling's illness		.739	
F23...understand the patient's current situation		.727	
F35...have medical procedures explained to them in a way they will understand		.718	
F4 ...know about the care their sick sibling needs		.671	
F7 ...are told how their sibling is when they are in hospital		.646	
F12...have spoken to the patient about their illness		.558	
F33...seem to understand when the situation is explained to them		.545	
F53...show affection toward their sick sibling			.748
F41 ...are understanding toward the patient			.658
F43...participate in caring for their sick sibling when they are at home			.642
F49...protect their sibling from falls, blows, or other things that may injure them			.633
F51...they encourage the patient to take care of their health			.627
F42...show rejection of their sick sibling			.588
F39...speak to the patient on the telephone, or send them letters when they are in the hospital			.503
F27...cooperate with household activities as much as they can			.486
F29...want to visit their sibling in hospital			.473
F10...play or spend time with their sick sibling			.470

*This phrase appears in each of the items on the filial subsystem.

Data analysis

For the content validity, the percentage of interjudge agreement was obtained. For construct validity, we assessed the discriminative power of the questions by comparing the means with the t test for independent samples (between the carers who responded with low scores and those who responded with high scores). Exploratory factorial analyses were performed for each section. Coefficients of Cronbach's alpha were obtained for each factor of the general system and the subsystems, as well as for each section in total. Ver-

sion 20 of the SPSS statistics software package was used for data analysis.

RESULTS

Table 1 shows the characteristics of the participating families, which notes that 87% of primary carers were mothers, approximately half were from Mexico City or Mexico State, and the other half were from other states. One third were oncological or hematological patients.

Table 6. Number of items for each subsystem and operational definitions of the factors obtained for the eSisFam

Section	Factors	No. of items	Operational definition
General (42)	Cohesion	20	Assesses the union between family members, and the support they give to the primary carer while they are with the patient in the hospital. Collaborative attitude of the members as though the situation with the illness affects them all. Joint agreements to solve the demands of the condition in the current stage of the same.
	Communication	10	Assesses the expression of thoughts and feelings of family members about the patient's illness at this stage of the same.
	Adaptation	12	Assesses the family's capacity to modify its habits and customs, organize itself, follow hospital rules, and try to carry on with normal daily life during the current stage of the illness.
Marital (27)	Affective-sexual relationship	17	Assesses displays of care, affection, and understanding, as well as aspects of the sexual relationship between the primary carer and their partner (although this might not be the patient's father or paternal figure) during the current stage of the illness.
	Distancing-infidelity	10	Assesses attitudes of distancing and infidelity between the primary carer and their partner (although this might not be the patient's father or paternal figure) during the current stage of the illness.
Parental (35)	Wellbeing	16	Assesses the physical and emotional health of the parental partnership at the current stage of the illness.
	Shared responsibility	12	Assesses how much the parental couple shares responsibility for the sick child and the home during the current stage of the illness.
	Care of siblings	7	Assesses the care or abandonment of siblings while the paternal figures care for the patient, at the current stage of the illness.
Filial (40)	Wellbeing	19	Assesses the physical and emotional health of the patient's siblings, as well as behavioral and academic changes, in the current stage of the illness.
	Knowledge of the illness	11	Assesses whether the patient's siblings have clear, correct, and age-appropriate knowledge of the illness, the care required for the patient, and the medical treatment or procedures during the current stage of the illness.
	Acceptance-participation	10	Assesses siblings' care and acceptance of the patient, and their participation in care and at home during the current stage of the illness.

Content validity

All questions were accepted by the judges in their respective dimensions and certain observations were taken into account, such as changing one word for another, or making the drafting simpler. An interjudge agreement percentage of over 80% was obtained in the total of the questions for each dimension.

Construct validity

The t test showed that all questions on the general system and the marital subsystem discriminated between the high and low scores in the sample. In the parental subsystem, only one question did not discriminate, and in the filial, three did not; these were therefore eliminated.

Tables 2 through 5 show the factorial loads obtained in the exploratory analysis of the questions on the general system (cohesion, communication, and adaptation; explaining 37% of the variance). They also show the loads obtained for the marital (affective-sexual relationship and distancing-infidelity which explains 42.5% of the variance), parental (wellbeing, shared responsibility, and sibling care, which explains 48% of the variance), and filial subsystems (wellbe-

ing, knowledge of the illness, and acceptance-participation, which explains 40% of the variance). Questions with factorial loads less than 0.40 were eliminated, as were those which had high loads in two or more factors. After the factorial analysis there remained a total of 144 questions from the 210 originals, which made up the instrument for assessing the family system which we named eSisFam (appendix 1).

Table 6 presents the general system and the subsystems, with the number of final questions as well as the operational definitions corresponding to each factor obtained.

Reliability of internal consistency

Cronbach's alpha coefficients were obtained for each one of the factors as well as for the total of each section. Values over 0.80 were obtained (table 7).

DISCUSSION AND CONCLUSION

Having specific instruments to assess family subsystems in the context of chronic pediatric illness is necessary to better understand intra-familial situations which are altered when facing such a condition.⁶⁻⁹ Because of this, timely evaluation

Table 7. Cronbach's Alpha coefficients for the extracted factors and in total for each section

Subsystem	Factors	Number of items	Cronbach's Alpha coefficient	
			By factor	By subsystem
General	Cohesion	20	0.936	0.930
	Communication	10	0.855	
	Adaptation	12	0.812	
Marital	Affective-sexual relationship	17	0.929	0.926
	Distancing-infidelity	10	0.812	
Parental	Wellbeing	16	0.914	0.920
	Shared responsibility	12	0.903	
	Care of siblings	7	0.847	
Filial	Wellbeing	19	0.895	0.898
	Knowledge of the illness	11	0.908	
	Acceptance-participation	10	0.849	

of mental health services is required as an integral part of treating a hospitalized patient.²⁸

The instrument developed provides an assessment of the general system which evaluates the cohesion, communication, and adaptation of the family to the current situation of the illness. These factors are assessed in the majority of instruments on family functioning,¹⁹⁻²⁷ but they were not specifically developed for situations of chronic pediatric illness.

Because family subsystems are seriously affected by illness^{6,7} (for example, conflicts in the parents' partner relationship,^{29,30} when most of the responsibility is left to one person,^{31,32} or when siblings feel displaced or abandoned),³³⁻³⁵ this new instrument gives an assessment of the marital (affective-sexual relationship and distancing-infidelity), parental (wellbeing, shared responsibility, and sibling care), and filial subsystems (wellbeing, knowledge of the illness, and acceptance-participation). The evaluation of these three in the proposed and validated factors is the new contribution of this work to the field of family diagnosis.

It is pertinent to mention that using the computer to apply instruments is a supportive resource for early diagnosis in public hospitals with a high concentration of patients, where generally resources for assessing the psychosocial factors of an illness are limited.³³ On the other hand, with the growing use of electronic devices, in the future it will be possible to have a family profile or diagnosis for each patient quickly and efficiently. Furthermore, this form of application helped the participants to show interest and motivation to respond in a novel and dynamic way.

The instrument developed is valid and reliable for a general assessment of the family system and subsystems. The measurement can be used in a pediatric hospital for the early detection of family situations which may interfere with the medical treatment of the child or adolescent.

Limitations

The primary limitation of this work is not having applied each subsystem to the different members involved. It would

be ideal for the patients' siblings to respond to the questions on the filial subsystem, for the primary carers' partners to respond to the marital subsystem, and for the other parental figures to respond to the parental subsystem. This is because the validation that is presented is based exclusively on the perception of the primary carer on the family subsystems, which may reflect a very important bias in expressing their desires and not the reality. Due to almost half the families coming from other states in Mexico, and the father almost always working full time, it is not very feasible in the context of third treatment level public hospitals to have the other family members available.

Funding

None.

Conflict of interest

The authors do not declare any conflict of interest.

Acknowledgements

To Doctor Shoshana Berezon-Gorn of the Ramón de la Fuente Muñiz National Institute of Psychiatry and to Doctor Javier Aguilar-Hernández of the School of Psychology at the UNAM, for their valuable methodological advice. To the clinical psychologists and pedopsychiatrists who participated as judges.

REFERENCES

1. Foley B, Barakat LP, Herman-Liu A, Radcliffe J et al. The impact of childhood hypothalamic/chiasmatic brain tumors in child adjustment and family functioning. *Children's Health Care* 2000;29(3):209-223.
2. Patterson JM, Holm KE, Gurney JG. The impact of childhood cancer on the family: A qualitative analysis of strains, resource and coping behaviors. *Psycho-Oncology* 2004;13:390-407.
3. Fanos J, Fahrner K, Jelveh M, King R et al. The sibling center: A pilot program for siblings of children and adolescents with a serious medical condition. *J Pediatrics* 2005;143:831-835.
4. Van Dyck PC, Kogan MD, McPherson MG, Weissman GR et al. Prevalence and characteristic of children with special health care needs (reprinted). *Archives Child Health, Pediatrics Adolescent Medicine* 2004;158:884-890.

5. McClellan CB, Cohen LL. Family functioning in children with chronic illness compared with healthy controls: a critical review. *J Pediatrics* 2007;150:221-223.
6. Minuchin S. *Familias y terapia familiar*. Argentina: Editorial Gedisa; 1974.
7. Williams PD, Williams AR, Graff JC, Hanson S et al. Interrelationships among variables affecting well siblings and mothers in families with a chronic illness or disability. *J Behavioral Medicine* 2002;25:411-424.
8. Ramos B, Aldereguía J. *Medicina social y salud pública en Cuba*. Ciudad de la Habana: Editorial Pueblo y Educación; 1990.
9. Roca MA, Pérez M. *Apoyo social. Su significación para la salud humana*. La Habana Cuba: Editorial Félix Varela; 2000.
10. Taylor SE. *Psicología de la salud*. México: McGraw-Hill/Interamericana Editores; 2007.
11. Cordaro G, Veneroni L, Massimino M, Clerici CA. Assessing psychological adjustment in siblings of children with cancer: parents' perspectives. *Cancer Nursing* 2012;35(1):42-50.
12. Ten Hoedt AE, Maurice-Stam H, Boelen CCA, Rubio-Gozalbo ME et al. Parenting a child with phenylketonuria or galactosemia: implications for health-related quality of life. *J Inheritable Metabolic Disease* 2011;34:391-398.
13. Kao B, Plante W, Lobato D. The use of the Impact on Sibling Scale with families of children with chronic illness and developmental disability. *Child: Care, Health Development* 2009;35(4):505-509.
14. Williams PD, Ridder EL, Setter RD, Liebergen A. Pediatric chronic illness (cancer, cystic fibrosis) effects on well siblings: parents' voices. *Comprehensive Pediatric Nursing* 2009;32:94-113.
15. Hopia H, Tomlinson PS, Paavilainen E, Astedt-Kurki P. Child in hospital: family experiences and expectations of how nurses can promote family health. *J Clinical Nursing* 2005;14:212-222.
16. Garro A, Thurman SK, Kerwin ME, Ducette JP. Parent/caregiver stress during pediatric hospitalization for chronic feeding problems. *J Pediatric Nursing* 2005;20:268-275.
17. Pelechano V. Calidad de vida, familia y afrontamiento en la enfermedad física crónica: Datos y sugerencias para un modelo. En: Buendía J (ed.). *Familia y psicología de la salud*. Madrid: Pirámide; 1999.
18. Lanzarote MD, Torrado E. Orientación y psicoterapia familiar con niños y adolescentes con enfermedad crónica. *Apuntes Psicología* 2009;27(23):457-471.
19. Epstein NB, Baldwin LM, Bishop DS. The McMaster family assessment device. *J Marital Family Therapy* 1983;9:171-180.
20. García-Mendez M, Rivera-Aragón S, Reyes-Lagunes I, Díaz-Loving R. Construcción de una escala de funcionamiento familiar. *Revista Iberoamericana Diagnóstico Evaluación Psicológica* 2006;22(2):91-110.
21. Moos RH, Moos BS, Trickett E. *Escalas de clima social*. Madrid: Tea Ediciones; 1995.
22. Olson DH, Russell C, Sprenkle DH. Circumplex model of marital and family systems II: Empirical studies and clinical intervention. *Advances Family Intervention, Assessment Theory* 1989;1:129-176.
23. Palomar J. *Funcionamiento familiar y calidad de vida*. Tesis de doctorado en psicología. Facultad de Psicología. Universidad Nacional Autónoma de México. México, DF; 1998.
24. Smilkstein G. The family APGAR: A proposal for a family function test and its used by physicians. *J Family Practice* 1978;6:12-31.
25. Villatoro JA, Andrade P, Fleiz C, Medina-Mora ME et al. La relación padres-hijos: una escala para evaluar el ambiente familiar de los adolescentes. *Salud Mental* 1997;20:2-27.
26. Montero Pardo X. *Enfermedad crónica y familia*. Tesis para obtener el grado de maestra en psicología. Facultad de Psicología, Universidad Nacional Autónoma de México. México, DF; 2009.
27. De la Cuesta D, Pérez E, Louro I, Bayarre H. Un instrumento de funcionamiento familiar para el médico de la familia. *Revista Cubana Medicina General Integral* 1996;12(1):24-3:24-31.
28. Saucedá JM. Lineamientos para evaluar la vida en familia. *Revista Médica IMSS* 1995;33:249-256.
29. Backalarz. La familia frente a la enfermedad crónica. Charla brindada en el Seminario de Actualización sobre Neurofibromatosis. 2007. Available at: <http://www.aanf.org.ar/documento/13.pdf> (Access date: February, 2012).
30. Morrod D. Make or break – who cares for couples when their children are sick? *Sexual Relationship Therapy* 2004;19(3):247-263.
31. Nagy S, Ungerer J. The adaptation of mothers and fathers to children with cystic fibrosis: a comparison. *Children's Health Care* 1990;9(3):147-154.
32. Rolland JS. *Familias, enfermedad y discapacidad. Una propuesta desde la terapia sistémica*. Barcelona: Gedisa; 2000.
33. Saucedá JM, Morales ME, Anaya A, Escalante P et al. Aportaciones de la psiquiatría de enlace a la pediatría integral. *Revista Médica IMSS* 1995;33:353-359.
34. Packman W, Mazaheri M, Sporri L, Long JK et al. Projective drawings as measures of psychological functioning in siblings with an intellectual disability: Parental perspectives in two disorders. *J Intellectual Disability Research* 2008;52:216-229.
35. Wilkens K, Woodgate R. A review of qualitative research on the childhood cancer experience from the perspective of siblings: A need to give them voice. *J Pediatric Oncology* 2005;22:305-319.

APPENDIX 1. Assessment of family subsystems of pediatric patients hospitalized due to chronic illness (eSisFam)

General system		Never	Some-times	Almost always	Always
	At this stage of the illness, in our family...				
1	...we stay in touch to know how everything is going				
2	...we have the support of our family members				
3	...we show both positive and negative feelings				
4	...we can talk openly about what we think about the illness				
5	...we are able to seek help from other people				
6	...we are able to make decisions that benefit the family				
7	...things are generally happy despite the illness				
8	...we talk about how we feel about the illness				
9	...we listen to different points of view about the illness				
10	...we plan activities to meet the needs of the family				
11	...everybody's interests and needs are important				
12	...when someone feels angry about the patient's situation, they can express it				
13	...we can talk to each other about how sad we feel				
14	...we have been able to organize our activities to deal with the illness				
15	...we know when a change is necessary in the family				
16	...we can express our sadness by crying				
17	...we feel bad crying in front of other people				
18	...it has been difficult to accept that this is happening to us				
19	...the primary carer stays in touch with other family members				
20	...each member takes on the responsibility that applies to them				
21	...despite the illness, we have time to listen to each other				
22	...we are not afraid to talk about the illness and the treatment				
23	...it is difficult to follow hospital rules				
24	...we have been able to organize our home around the illness				
25	...we show the affection we feel for each other				
26	...we keep quiet about our feelings on what happens with the patient				
27	...the primary carer's needs are also important to the others				
28	...we find it hard to change our habits or routines				
29	...we think that the patient is everyone's responsibility				
30	...we are allowed to cry when we feel sad about the patient				
31	...we talk openly about what is happening to us				
32	...we think we are able to move ahead with this difficult situation				
33	...we plan activities to meet the needs of the patient				
34	...when we feel like crying, we do so				
35	...we talk about what might happen to the patient in the future				
36	...we fight or argue because of this situation				
37	...there is a union to confront the illness				
38	...we hide the gravity of the situation				
39	...we talk about the illness with our friends				
40	...we are "on another planet"				
41	...in spite of the difficult situation, we give ourselves time for fun				
42	...we talk about the patient's needs				
43	...it is difficult to agree about the illness				
44	...we support the person who takes care of the patient the most				
45	...it has been difficult for us to do different or new things because of the illness				
46	...although we might not be there, we are still interested in the patient's situation				
47	...when a problem comes up with the illness, we suggest solutions				
48	...it is important for us to keep informed about the illness				
49	...we are organized for visiting the patient in hospital				
50	...we try to live life as normally as possible				
51	...we keep any anger we feel about the situation inside				
52	...we meet the needs of the patient in agreement				
53	...when someone has a problem, the others try to help them				
54	...we support each other while the patient is in hospital				
55	...we make joint decisions for important matters of the illness				
56	...we have been able to modify our habits around the illness and hospitalization				
57	...we agree with hospital rules				
58	...we talk about the illness with neighbors or acquaintances				
59	...we can talk about the illness without fighting, despairing, or crying				
60	...it is important to stick together right now				
61	...some family members show distance or lack of interest				
62	...it has been difficult to stop doing things we did before				

Instructions: Use the mouse to click on the response that best describes the parents as a couple at this stage of the illness.

Translation of the original version published in spanish in: Salud Mental 2015, Vol. 38 Issue No. 4.

APPENDIX 1. Assessment of family subsystems of pediatric patients hospitalized due to chronic illness (eSisFam) (Continued)

Marital subsystem		Never	Some-times	Almost always	Always
	At this stage of the illness, as a couple...				
1	...we have time to spend together				
2	...we have stopped taking care of ourselves to look after the patient				
3	...our sexuality is important				
4	...we understand how the other feels				
5	...we try to conserve our intimate space				
6	...the illness caused our separation				
7	...we avoid the subject of our sexuality				
8	...we can mutually enjoy ourselves at this time				
9	...we show the love we feel towards each other				
10	...the illness has affected our privacy				
11	...we express affection				
12	...we have shown sexual interest in other people				
13	...we comfort each other				
14	...we can be sexually satisfied				
15	...one of us feels displaced by the patient				
16	...our sick child comes before us				
17	...there has been infidelity				
18	...we try to devote time to each other				
19	...we are interested in our sexual relationship				
20	...we have emotionally distanced ourselves from one another				
21	...we have time to go out alone				
22	...the quality of our sexual relations has gone down				
23	...we have been at the point of divorce because of the illness				
24	...we can feel passionate towards each other				
25	...we are distant because one is at the hospital and the other is working				
26	...we motivate each other to keep going in this situation				
27	...we believe we should have fun as a couple				
28	...we have reduced our sexual relations				
29	...we feel guilty for enjoying our sexual relationship				
30	...one of us says the illness is a pretext to deceive the other				
31	...we show sexual interest in each other				
32	...we are attractive to each other				
33	...if one is unfaithful, they think the other is, too				
34	...we have been interested in other people				

Instructions: Use the mouse to click on the response that best describes the parents (or parental figures) in their role as the patient's parents at this stage of the illness.

APPENDIX 1. Assessment of family subsystems of pediatric patients hospitalized due to chronic illness (eSisFam) (Continued)

Parental subsystem		Never	Some-times	Almost always	Always
	En esta etapa de la enfermedad, como padres...				
1	...we share the responsibility of the illness				
2	...we know how the patient's siblings feel				
3	...we have had problems sleeping				
4	...we share the responsibility for other children at home				
5	...we believe that the needs of our healthy children come second now				
6	...we have disregarded our own health because of caring for the patient				
7	...we both feel responsible for our home				
8	...we agree on what to do for the patient				
9	...we have altered our diet				
10	...we have control of the situation				
11	...we agree on caring for our other children				
12	...we share what is required to deal with the illness				
13	...we organize home activities by mutual agreement				
14	...we have often been sick ourselves				
15	...we support each other with housework				
16	...while one is at the hospital, there is someone to look after the other children				
17	...we are only dedicated to the patient, as the other children can wait				
18	...one of us carries the load of this situation more than the other				
19	...we both stay abreast of the patient and their condition				
20	...we meet the needs of our other children				
21	...we are on the lookout for medical sign				
22	...we are responsible for the needs of our other children				
23	...we are informed of what happens with the patient in hospital				
24	...we provide financial support				
25	...we provide moral support				
26	...we believe that our healthy children need more attention				
27	...we support each other in decisions about medical procedures				
28	...we feel we are to blame for our child's illness				
29	...we are bothered that our healthy children do not understand this situation				
30	...although one is absent from the hospital, they stay abreast of the situation				
31	...one blames the other for our child's illness				
32	...we feel frustrated by the illness				
33	...we believe we pay enough attention to the other children				
34	...we have suffered headaches, stomach pains, body pains, or other discomfort				
35	...this difficult situation makes us angry				
36	...we feel that our healthy children want more attention than we can give them				
37	...we feel powerless against our child's illness				
38	...we indulge our sick child more than their siblings				
39	...we are downhearted by the situation with our child				
40	...we take the other children's opinions into account				
41	...we are depressed				
42	...we listen to our other children when they want to talk				
43	...we are anxious				
44	...we show affection toward our other children				
45	...we are worried				
46	...we meet the needs of our healthy children even though their sibling is in hospital				
47	...we are desperate				
48	...one or both of us has become ill because of this situation				
49	...we have had to abandon our other children to care for the patient				
50	...one or both of us is tired or worn out by this situation				
51	...we know how our children feel about their sick sibling				
52	...when we feel unwell, we go to the doctor				
53	...we understand the moods of our healthy children				
54	...we go to routine medical checkups (dentist, Ob-Gyn, etc.)				

Instructions: Use the mouse to click on the response that best describes the parents (or parental figures) in their role as the patient's parents at this stage of the illness.

**APPENDIX 1. Assessment of family subsystems
of pediatric patients hospitalized due to chronic illness (eSisFam) (Continuación)**

Filial subsystem		Never	Some- times	Almost always	Always
	At this stage of the illness, the patient's siblings...				
1	...have knowledge about their sibling's illness				
2	...help around the house while we are at the hospital				
3	...have had sudden mood changes				
4	...know about the care their sick sibling needs				
5	...understand that we are busy with their sibling in hospital				
6	...have frequently been sick				
7	...are told how their sibling is when they are in hospital				
8	...have had behavioral problems				
9	...dislike participating in their sibling's care when they are at home				
10	...play or spend time with their sick sibling				
11	...have been aggressive or rebellious				
12	...have spoken to the patient about their illness				
13	...have shown jealousy because of the attention we give the patient				
14	...ask as a complaint: "why does my sibling have this illness?"				
15	...have had lower grades at school				
16	...get anxious about what could happen to their sibling's life				
17	...have been angry about their sibling's situation				
18	...have suffered headaches, stomach pains, body pains, or other discomfort				
19	...know what the illness consists of				
20	...have had insomnia, nightmares, or other sleep problems				
21	...have clear information about the illness				
22	...have felt to blame for their sibling's illness				
23	...understand the patient's current situation				
24	...have found it difficult to stay in someone else's care				
25	...have us clearly explain the treatment to them in a way they will understand				
26	...envy the affection or attention we show towards our sick child				
27	...cooperate with household activities as much as they can				
28	...say that we spoil their sick child more than them				
29	...want to visit their sibling in hospital				
30	...are afraid of getting ill like their sibling				
31	...have correct information about the illness				
32	...have shown resentment towards their sick sibling				
33	...seem to understand when the situation is explained to them				
34	...have expressed loneliness because their sibling is not around				
35	...have medical procedures explained to them in a way they will understand				
36	...have been downhearted				
37	...have had problems with their eating habits				
38	...have become fearful				
39	...speak to the patient on the telephone, or send them letters when they are in the hospital				
40	...have felt alone because their parents are in hospital				
41	...are understanding towards the patient				
42	...show rejection of their sick sibling				
43	...participate in caring for their sick sibling when they are at home				
44	...are intolerant of their sick sibling				
45	...are ashamed of their sick sibling				
46	...have isolated themselves from others				
47	...have shown acceptance of their sick sibling				
48	...express feeling that they are sick like the patient				
49	...protect their sibling from falls, hits, or other things that may injure them				
50	...have become anxious				
51	...encourage the patient to take care of their health				
52	...have had some of their activities affected because of the illness				
53	...show affection towards their sick sibling				
54	...have expressed feeling guilty for being healthy themselves				
55	...have been lied to by us, because of the gravity of the illness				
56	...treat their sick sibling like a normal person				
57	...are bothered by the attention we pay to their sick sibling				
58	...have tried to blackmail or manipulate things, taking advantage of the situation				
59	...are calm in the face of the situation				