



## Semana de Congresos y Jornadas Nacionales 2017

*"Por un niño sano en un mundo mejor"*

24, 25, 26, 27 y 28 de abril de 2017

Panamericano Buenos Aires Hotel & Resort – Carlos Pellegrini 551 – Ciudad de Buenos Aires

EXE Hotel Colón – Carlos Pellegrini 507 - Ciudad de Buenos Aires



# Estrés y Agotamiento de los cuidadores

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**Hospital de Niños Pedro de Elizalde**

# Estrés y Agotamiento de los cuidadores

¿Quiénes son los cuidadores?



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# MODERN FAMILY

# Estrés y Agotamiento de los cuidadores

¿Qué es estrés y agotamiento?

**Burn Out**

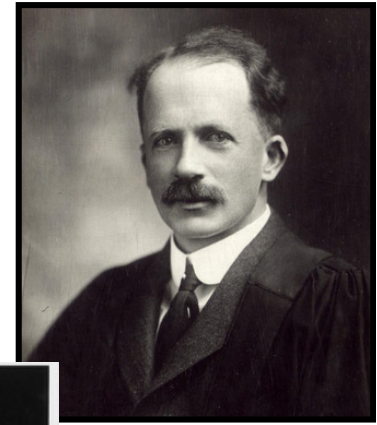


# Estrés- Agotamiento

- El **Estrés** es la respuesta que da nuestro cuerpo ante diversas situaciones que provocan tensión suficiente como para considerarlas una amenaza.
- **Agotamiento** es el acto y la consecuencia de **agotar**: consumir, gastar o vaciar la totalidad de algo, provocar un cansancio extremo.



Verano de 1921...



## Estrés- Agotamiento- Burnout.

- Con el descubrimiento de la insulina la diabetes tipo 1 paso de ser una enfermedad aguda y mortal a una enfermedad crónica con posibles episodios de descompensación aguda.

El estrés y el agotamiento se superponen.

# Objetivos a trabajar

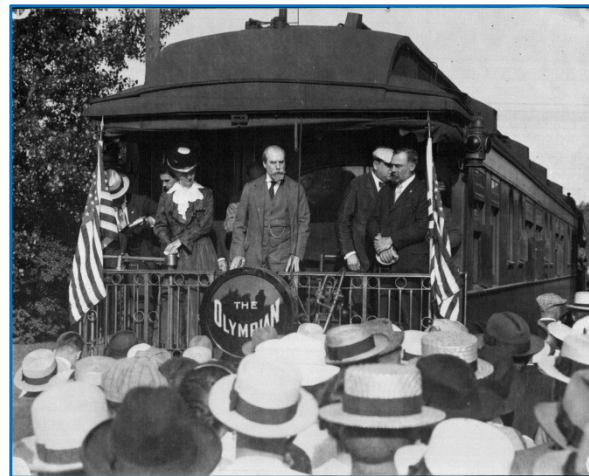
- Como atemperar el estrés inicial.
- Como prevenir el agotamiento.
- Como favorecer la separación y la autonomía.

# Debut-Onset

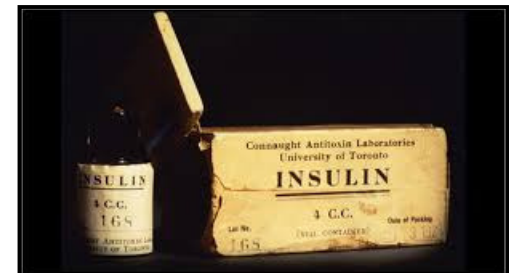
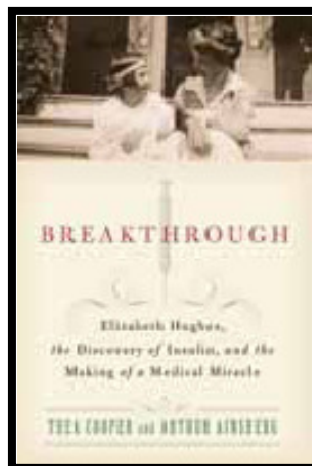
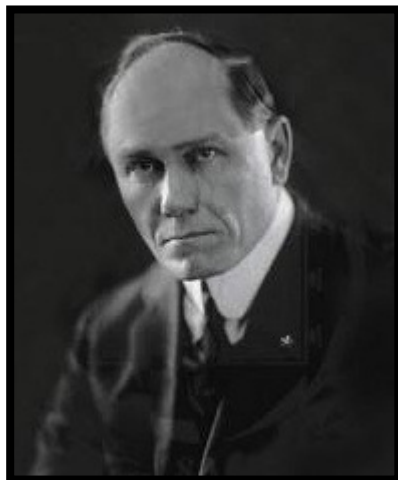
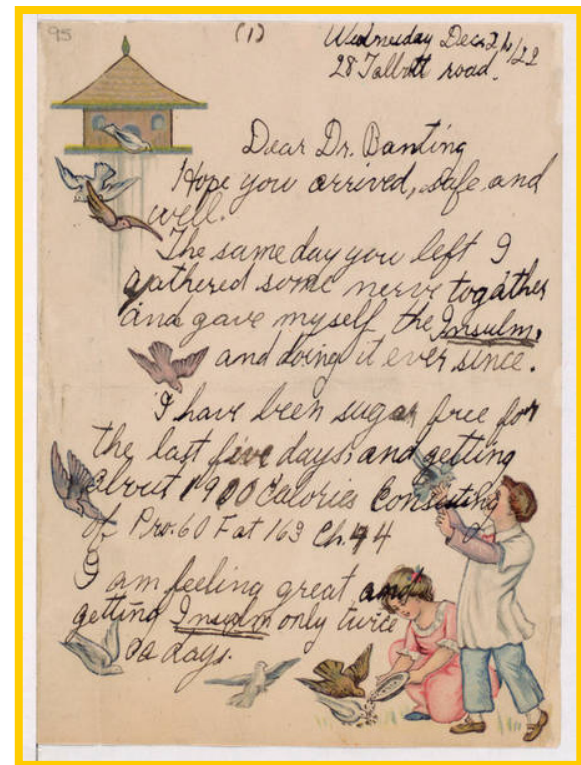
- Primera actuación en público de una compañía teatral o de un artista.
- La primera vez en una actividad .

La aparición de la diabetes es brusca y definitiva.





Despite coming close to winning the presidency in 1916 Hughes did not seek the Republican nomination again in 1920.



# Dificultades al debut

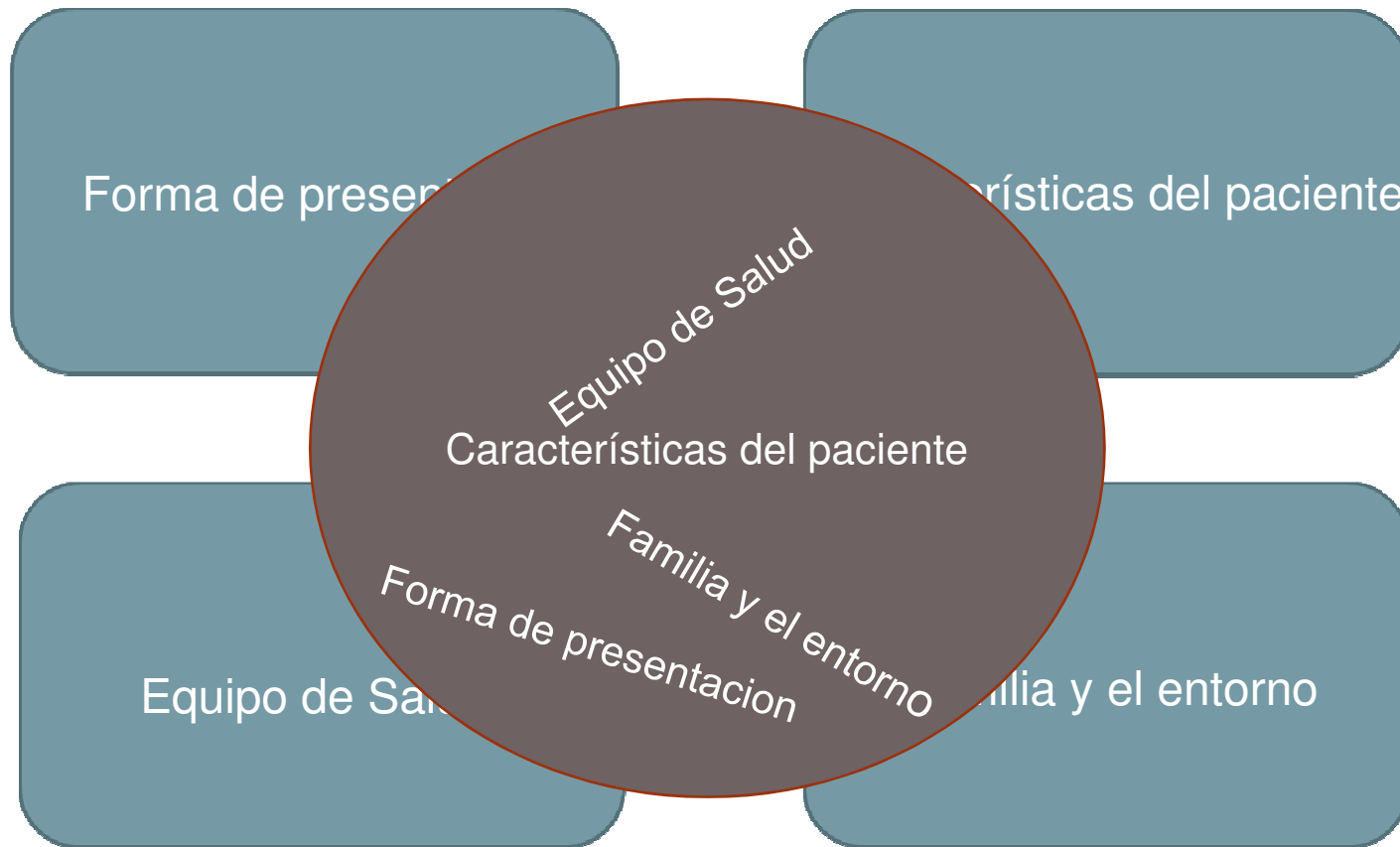
Forma de presentacion

Características del paciente

Equipo de Salud

Familia y el entorno

# Dificultades al debut





# Al debut

- Tener en cuenta los sentimientos iniciales
- Si bien se necesita cierto grado de alerta para aprender, la información nueva es múltiple y compleja.

Los sentimientos iniciales se reiteran en cada momento de cambio durante la evolución.

# Estres al diagnostico

Los sentimientos de los padres/del cuidador sobre y/o las respuestas al diagnóstico de diabetes tipo 1 en un niño pueden incluir:

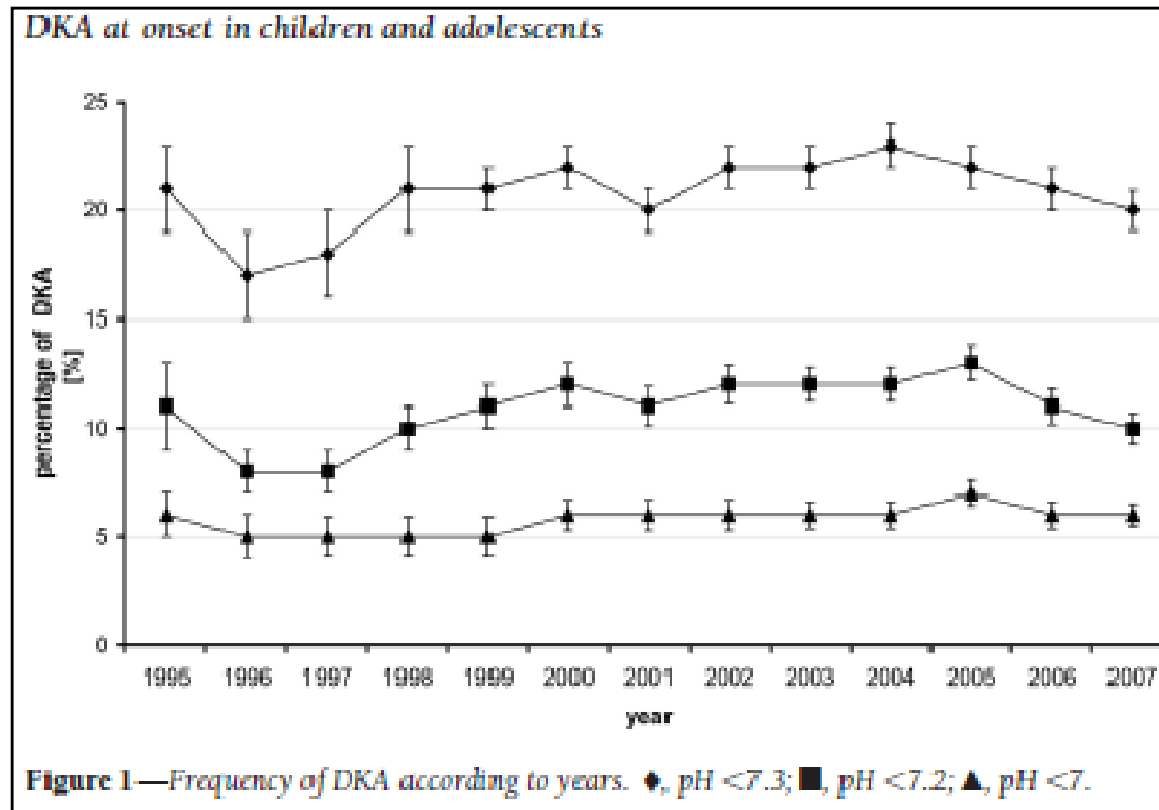
- Shock<sup>1</sup>
- Tristeza<sup>2</sup>
- Pena<sup>2</sup>
- Temor<sup>3</sup>
- Culpa<sup>3</sup>
- Ansiedad<sup>3</sup>
- Distrés emocional<sup>3</sup>
- Agobio<sup>4</sup>
- Frustración<sup>3,5</sup>
- Preparación para la enfermedad<sup>3</sup>
- Sentido de pérdida<sup>1</sup>
- Desconfianza<sup>5</sup>

Debido a la severidad de la enfermedad y a un mayor riesgo de morbilidad y mortalidad cuando un niño presenta cetoacidosis diabética (CAD) en el momento del diagnóstico,<sup>6,7</sup> puede resultar más estresante para los cuidadores.

1. Lowes L, et al. *Diabet Med.* 2004;21(6):531-538. 2. Wennick A, Hallström I. *J Fam Nurs.* 2006;12(4):368-389.  
3. Whittemore R, et al. *Diabetes Educ.* 2012;38(4):562-579. 4. Beck J, et al. *Diabetes Educ.* 2012;38(2):280-288.  
5. Smaldone A, Ritholz MD. *J Pediatr Health Care.* 2011;25(2):87-95. 6. Rodacki M, et al. *Diabetes Res Clin Pract.* 2007;78:259-262. 7. Daneman D, et al. *Ped Child Health.* 1999;4(1)57-63.

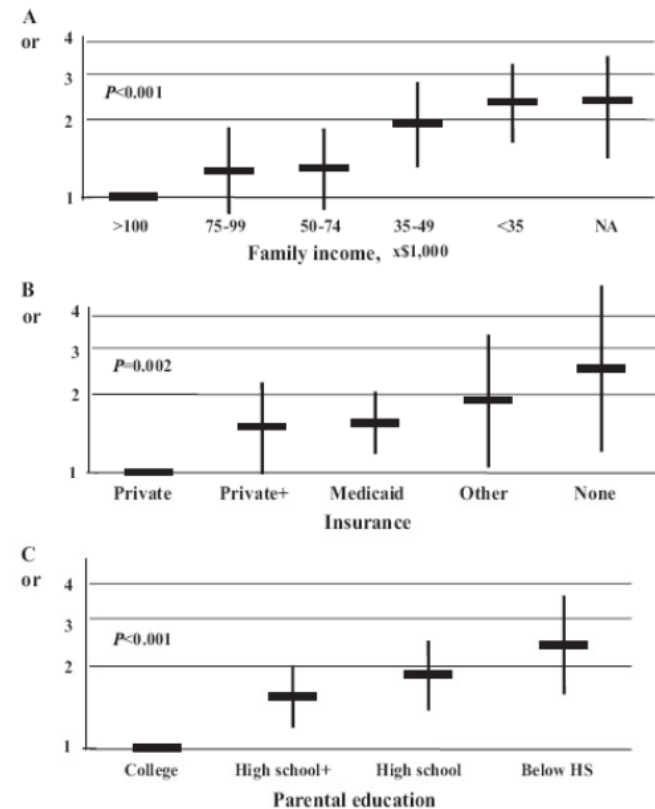
# Ketoacidosis at Diabetes Onset Is Still Frequent in Children and Adolescents

A multicenter analysis of 14,664 patients from 106 institutions



**Table 1**  
**Frequency of diabetic ketoacidosis at disease onset of type 1 diabetes mellitus**

Country	Diabetic Ketoacidosis (%)
United Arab Emirates	80
Romania	67
Saudi Arabia	40–77
France	54
Kuwait	38–49
Poland	33–54
China	42
Oman	42
Lithuania	35
Austria	37
Italy	32–41
Bulgaria	35
Germany	26–53
United States	27–44
Turkey	29
United Kingdom	25–38
Ireland	25
Finland	19–22
Canada	18.6
Sweden	13–14



**FIGURE 2**  
Relationship between annual family income (A), insurance type (B), or parental education (C) and the presence of DKA at diagnosis of diabetes in youth. ORs and the 95% CIs were adjusted for center, age, gender, race or ethnicity, type of diabetes, and family history of diabetes.

# Internación al debut o manejo ambulatorio

Al inicio de su enfermedad el paciente debe tener un período de contacto estrecho con el equipo tratante, que será con internación o ambulatorio según la situación particular de la institución y la familia del paciente.

- Siempre serán hospitalizados los niños:
  - menores de 2 años de edad.
  - Los que vivan lejos del Centro de Referencia
  - Familias de riesgo (dificultades socioeconómicas importantes o trastornos emocionales severos)
  - Los que presenten otras patologías agregadas (infecciones, desnutrición grave, etc.)
  - Los que no tengan tolerancia gástrica
  - Cetosis aunque sea leve

El período de internación es variable, estimándose un término medio de 7 a 15 días, con el objeto de ajustar la dosis de insulina a los requerimientos del paciente y realizar educación diabetológica y contención psico-social que permita a la familia continuar el tratamiento domiciliario.

## La comunicacion del diagnostico: Nunca hay una segunda posibilidad para una primera impresión

- Una vez que el médico diagnostica una enfermedad crónica en un niño, sus padres tienden a recordar más tarde:
  - El evento<sup>1</sup>
  - Cómo se sintieron<sup>2</sup>
- Es importante asegurar la comprensión de la situación:
  - en forma precisa<sup>3</sup>
  - en forma efectiva<sup>1</sup>
  - mostrando empatía<sup>1</sup>

# Cómo dar las malas noticias:

## Posibles consideraciones:

- ❑ Decidir quién debería estar presente.<sup>1</sup>
- ❑ Elegir un entorno adecuado.<sup>1-3</sup>
- ❑ Comunicar la información con claridad.<sup>1,3</sup>
- ❑ Demostrar empatía, preocupación y compasión.<sup>1</sup>
- ❑ Individualizar su abordaje.<sup>1,3</sup>
- ❑ Otorgarle a los papas tiempo para que en soledad puedan absorber la información, reaccionar y formular preguntas.<sup>1,3</sup>

- No dar mas informacion que la necesaria o solicitada.
- No calmar nuestra propia ansiedad.
- Hacer sentir a la familia que estamos disponibles.

# American Diabetes Association

## **The crisis of diagnosis**

The diagnosis of diabetes is a time of crisis for the child and the family. The diagnosis has an initial psychological impact on the individual, their siblings and parents. Indeed, the diagnosis may exacerbate preexisting problems. Poor initial adaptation, with depression, anxiety and low self-esteem, predicts later psychological difficulties (8). The ability of the family to provide support for the child varies depending on the educational, economic and emotional resources of the family. Although some families may take the diagnosis in their stride and manage the new responsibility well, other families at diagnosis have known risk factors for poor diabetes control, including single-parent families, families living in poverty and parents coping with other major stressful life events. These families may require extra time, education, attention and financial assistance at diagnosis. Some parents may require help to address faulty ideas such as personal shame or guilt over having a child with diabetes (Table 1).

- Crisis familiar.
- Ansiedad, depresión  
disminución de la autoestima.
- Profundiza conflictos previos.
- Factores de riesgo pobreza,  
perdidas anteriores, soledad.



# Consideraciones al debut

- Aceptar lo inevitable

*Enfrentar el diagnostico*

- Aceptar la tristeza

*« Mi hija dice que lo mas dificil de la diabetes es ver a la mama llorar por los rincones»*

- Prepararse para volver a casa.

*No decir la vida sigue igual.*

- Reconstruir la vida con nuevas rutinas

*«Vivir con el reloj»*

# El diagnóstico de diabetes tipo 1 cambia la vida

**En el momento del diagnóstico, los niños y sus padres rápidamente deberían:**

- Comprender información compleja<sup>1,3</sup>
- Repensar el estilo de vida de su familia<sup>2</sup>
- Aprender capacidades específicas de supervivencia, esto incluye ser capaz de<sup>3</sup>:
  - Administrar insulina.
  - Identificar y manejar episodios de hipoglucemia e hiperglucemia que posiblemente pongan en riesgo la vida.
  - Calcular el contenido de carbohidratos de los alimentos y planificar horarios para actividades y comidas.

# Lista de responsabilidades de manejo diarias de los padres/cuidadores

Las habilidades que deben tener los cuidadores de un niño con diagnóstico reciente de diabetes tipo 1 se dividen en 4 categorías principales<sup>1,2</sup>:

## Manejo de la condición

- Cuidado práctico
- Monitoreo e interpretación de signos y síntomas
- Resolución de problemas
- Toma de decisiones

## Cómo mantener la unidad familiar

- Equilibrar la diabetes tipo 1 y las demandas familiares.
- Intentar satisfacer las necesidades de salud y el desarrollo de cada miembro de la familia.

## Identificar, acceder a y coordinar recursos

- Evaluar y negociar recursos de la comunidad, eso incluye a los profesionales de la salud.

## Mantener el Yo

- Salud mental
- Bienestar emocional
- Salud espiritual

**Table 1. Parent/Caregiver Responsibilities and Activities Associated with the Day-to-Day Management of Raising a Child who has a Chronic Condition**

Learning about the condition and care	5. Involves child in care as developmentally appropriate
1. Develops working knowledge of disease process	6. Uses a system for remembering when actions are due
2. Develops working knowledge of treatment plan	7. Has ability to take action on multiple issues at once
<b>A. Monitoring condition &amp; behavior</b>	<b>F. Making treatment adjustments/problem-solving</b>
1. Identifies subtle changes in condition and behavior	1. Identifies and defines problem(s) that need alternative solution(s)
2. Observes verbal and nonverbal indicators	2. Decides what part of care or task needs to be altered/changed
3. Uses instruments to monitor condition when appropriate	3. Considers possible solutions
4. Uses appropriate level of vigilance	4. Tries multiple strategies until a solution to problem found
5. Makes accurate observations	5. Reacts appropriately to symptom changes
6. Keeps written record when appropriate	6. Modifies routines to accommodate illness situation
7. Notices patterns of responses	7. Modifies environment to accommodate illness situation
<b>B. Interpreting</b>	8. Adjusts care to optimize comfort and symptom management, including
1. Recognizes deviations from normal	a. amount of food
2. Recognizes something is "different" or wrong	b. PRN medications
3. Recognizes seriousness of a problem	c. rest
4. Seeks explanation for unexplained signs & symptoms	d. exercise
5. Asks questions to assist in developing explanation	9. Calls for expert information when appropriate
6. Makes correct attributions	10. Knows which health care team member to call when necessary
7. Uses a reference point in making sense of observations	11. Uses mistakes as an opportunity for learning
8. Considers multiple explanations for an observation	12. Considers what led to mistakes, and alters what appears to be source of problem
<b>C. Providing hands-on care</b>	13. Searches for an alternative when one illness care strategy no longer works
1. Maintains adherence to treatment plan	14. Uses creativity in problem-solving
2. Performs personal care safely	15. Deals with emergency situations appropriately
a. bathing	16. Evaluates outcomes
b. feeding	<b>G. Guiding or coaching child in self-care: striving for interdependence versus control</b>
c. dressing	<b>H. Teaching others how to care for child (e.g. teachers, sitters, family members)</b>
d. ADLs	<b>II. Identifying, accessing, and coordinating resources</b>
3. Performs condition-related treatments safely	<b>A. Assessing needs and strengths</b>
a. administers medications	1. Takes initiative in seeking resources
b. administers treatments	2. Seeks resources wisely: casts a wide net
c. tube care/management	3. Seeks authoritative advice when appropriate
d. stoma care/management	4. Uses advice judiciously
e. dressings	5. Weeds out erroneous, inaccurate, or inadequate advice (including internet)
f. equipment care/management	6. Persists in obtaining resources until finding what is really needed
4. Provides emotional/developmental support	7. Determines which providers are most accessible, helpful, and knowledgeable
a. spends time with child	8. Makes own needs known
b. plays with child	9. Considers the following resources in quest to meet child's and family units needs
c. provides developmentally appropriate activities	a. primary care
d. offers developmentally appropriate guidance, including "coaching"	b. specialized care
e. anticipates needs of child within a developmental context	c. home care services
f. supports spiritual development	d. babysitting
<b>D. Making decisions</b>	e. respite
1. Takes into account multiple care demands	f. daycare
2. Weighs competing demands	g. school services
3. Weighs the importance of conflicting priorities	h. social opportunities
4. Attends to multiple care issues at once	i. sports
5. Thinks ahead about possible consequences of a given action	j. special camp experiences
<b>E. Developing care routines</b>	
1. Uses effective reminders to time actions	
2. Uses timing to coordinate care needed	
3. Develops routines to manage complex tasks	
4. Takes child's characteristics into consideration when developing routine	

**Table 1. Parent/Caregiver Responsibilities and Activities Associated with the Day-to-Day Management of Raising a Child who has a Chronic Condition (continued)**

<b>B. Negotiating health-related issues (ability to advocate for child &amp; family)</b>	<b>E. Addresses individual family member &amp; family unit developmental needs (such as child and sibling "chauffeur," helping with homework, or in some cases coordination and provision of home schooling, coordination of social and recreational sports and activities, planning family activities and vacations)</b>
1. Expresses opinions with health care and school professionals	<b>F. Defines, and redefines, meaning of illness related to developmental milestones for the child, other family members, self, and the family unit</b>
2. Evaluates care received in the health care system	<b>G. Organizes family activities to include the child with a chronic condition</b>
3. Seeks assistance from health care team in a timely manner	<b>H. Integrates "couple" time into schedule (if 2 parent family)</b>
4. Works in partnership with the health care team	<b>I. Maintains the household (or coordinates efforts if performed by others)</b>
5. Works in partnership with home care services	1. Household maintenance and repair
6. Works in partnership with the school system	2. Meal preparation
7. Advocates for child and self when necessary	3. Cleaning
<b>C. Negotiating emergency plan</b>	4. Laundry
1. Develops an emergency plan in partnership with the health care team to address:	5. Errands
a. medical emergencies and complications	6. Grocery shopping
b. malfunctioning of medical equipment	7. Bill paying
c. power & electricity outages	8. Gardening
d. support person(s) illnesses	<b>J. Manages economic issues</b>
e. schools/daycare closures	1. Insurance companies
<b>D. Providing coordination of care</b>	2. Equipment & medication costs
1. "Concierge" or monitor for individual and family unit's physical, developmental, emotional, social, and spiritual needs	3. Special programs such as private tutoring, pt, ot, speech programs
2. Works in partnership with the health care team to develop a plan of home care	<b>IV. Maintaining self</b>
3. Works in partnership with insurance plan on case management if appropriate	<b>A. Meets personal physical and mental health care needs</b>
4. Identifies family, friends, and neighbors who can offer assistance	1. Regular check-ups
5. Accesses community-based resources	2. Sleep
a. equipment company	3. Exercise
b. home health agency	4. Balanced diet
c. pharmacy	5. Weekly time out
d. therapies	6. Recognition and expression of grief, other emotions
6. Maintains flexibility built into coordination plan	7. Spiritual needs
7. Develops back-up plans	<b>B. Expresses sense of capability in caregiving role</b>
8. Develops re-hospitalization plan as needed	<b>C. Identifies ways of relieving day-to-day stress</b>
9. Integrates primary care into care plan	<b>D. Addresses personal and career goals</b>
10. Identifies support groups	<b>E. Nurtures significant-other relationship &amp; other close friendships</b>
11. Develops respite care plan	
12. Explores alternative-care options as appropriate	
<b>III. Maintaining family unit</b>	
<b>A. Balances illness and family demands</b>	
<b>B. Continues to participate in family traditions, rituals, and routines</b>	
<b>C. Monitors family member health status</b>	
<b>D. Identifies family strengths</b>	

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a. bathing	16. Evaluates outcomes
b. feeding	<b>G. Guiding or coaching child in self-care: striving for interdependence versus control</b>
c. dressing	<b>H. Teaching others how to care for child (e.g. teachers, sitters, family members)</b>
d. ADLs	<b>II. Identifying, accessing, and coordinating resources</b>
3. Performs condition-related treatments safely	<b>A. Assessing needs and strengths</b>
a. administers medications	1. Takes initiative in seeking resources
b. administers treatments	2. Seeks resources wisely: casts a wide net
c. tube care/management	3. Seeks authoritative advice when appropriate
d. stoma care/management	4. Uses advice judiciously
e. dressings	5. Weeds out erroneous, inaccurate, or inadequate advice (including internet)
f. equipment care/management	6. Persists in obtaining resources until finding what is really needed
4. Provides emotional/developmental support	7. Determines which providers are most accessible, helpful, and knowledgeable
a. spends time with child	8. Makes own needs known
b. plays with child	9. Considers the following resources in quest to meet child's and family units needs
c. provides developmentally appropriate activities	a. primary care
d. offers developmentally appropriate guidance, including "coaching"	b. specialized care
e. anticipates needs of child within a developmental context	c. home care services
f. supports spiritual development	d. babysitting
<b>D. Making decisions</b>	e. respite
1. Takes into account multiple care demands	f. daycare
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5. Thinks ahead about possible consequences of a given action	j. special camp experiences
<b>E. Developing care routines</b>	
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3. Develops routines to manage complex tasks	
4. Takes child's characteristics into consideration when developing routine	

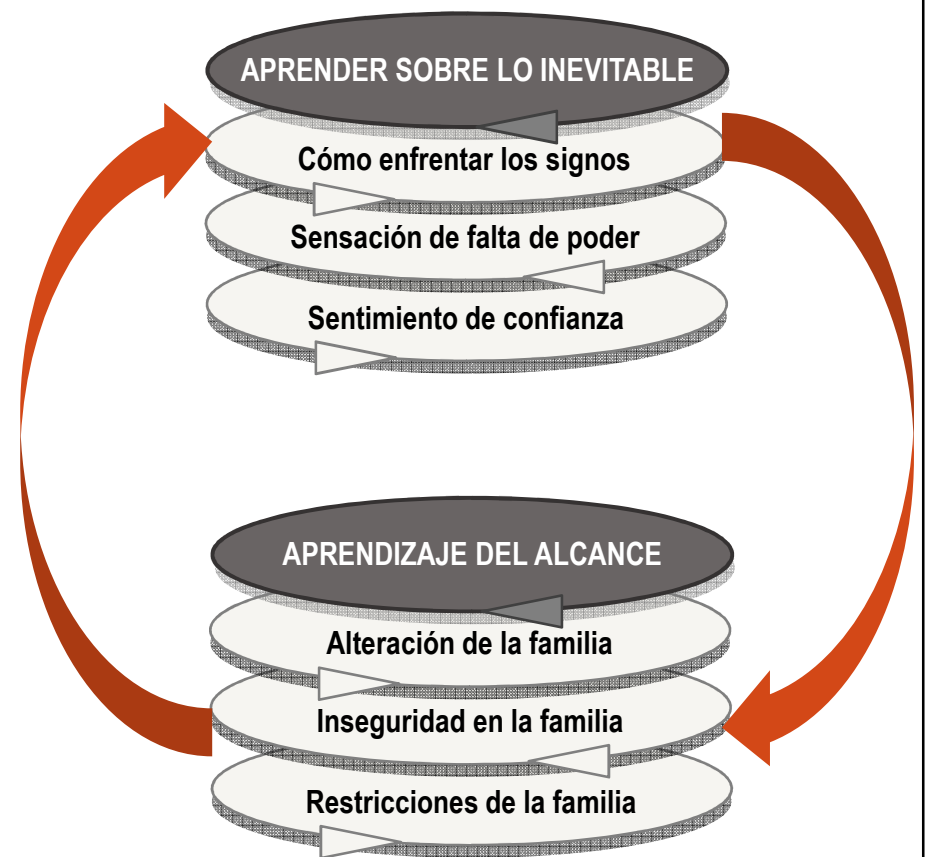
**Table 1. Parent/Caregiver Responsibilities and Activities Associated with the Day-to-Day Management of Raising a Child who has a Chronic Condition (continued)**

<b>B. Negotiating health-related issues (ability to advocate for child &amp; family)</b>	<b>E. Addresses individual family member &amp; family unit developmental needs (such as child and sibling "chauffeur," helping with homework, or in some cases coordination and provision of home schooling, coordination of social and recreational sports and activities, planning family activities and vacations)</b>
1. Expresses opinions with health care and school professionals	<b>F. Defines, and redefines, meaning of illness related to developmental milestones for the child, other family members, self, and the family unit</b>
2. Evaluates care received in the health care system	<b>G. Organizes family activities to include the child with a chronic condition</b>
3. Seeks assistance from health care team in a timely manner	<b>H. Integrates "couple" time into schedule (if 2 parent family)</b>
4. Works in partnership with the health care team	<b>I. Maintains the household (or coordinates efforts if performed by others)</b>
5. Works in partnership with home care services	1. Household maintenance and repair
6. Works in partnership with the school system	2. Meal preparation
7. Advocates for child and self when necessary	3. Cleaning
<b>C. Negotiating emergency plan</b>	4. Laundry
1. Develops an emergency plan in partnership with the health care team to address:	5. Errands
a. medical emergencies and complications	6. Grocery shopping
b. malfunctioning of medical equipment	<b>II. Managing economic issues</b>
c. power & electricity outages	1. Insurance companies
d. support person(s) illnesses	2. Equipment & medication costs
e. schools/daycare closures	3. Special programs such as private tutoring, pt, ot, speech programs
<b>D. Providing coordination of care</b>	<b>IV. Maintaining self</b>
1. "Concierge" or monitor for individual and family and spiritual needs	<b>A. Meets personal physical and mental health care needs</b>
2. Works in partnership with the health care team to develop a plan of home care	1. Regular check-ups
3. Works in partnership with insurance plan on case management if appropriate	2. Sleep
4. Identifies family, friends, and neighbors who can offer assistance	3. Exercise
<b>III. Accessing community-based resources</b>	4. Balanced diet
a. equipment company	5. Weekly time out
b. home health agency	6. Recognition and expression of grief, other emotions
c. pharmacy	7. Spiritual needs
d. therapies	<b>B. Expresses sense of capability in caregiving role</b>
6. Maintains flexibility built into coordination plan	<b>C. Identifies ways of relieving day-to-day stress</b>
7. Develops back-up plans	<b>D. Addresses personal and career goals</b>
8. Develops re-hospitalization plan as needed	<b>E. Nurtures significant-other relationship &amp; other close friendships</b>
9. Integrates primary care into care plan	
10. Identifies support groups	
11. Develops respite care plan	
12. Explores alternative-care options as appropriate	
<b>III. Maintaining family unit</b>	
<b>A. Balances illness and family demands</b>	
<b>B. Continues to participate in family traditions, rituals, and routines</b>	
<b>C. Monitors family member health status</b>	
<b>D. Identifies family strengths</b>	

? NO IS MUCHO?

# El diagnóstico de diabetes infantil tipo 1 es el comienzo de un proceso de aprendizaje

- La diabetes no es una enfermedad estática<sup>1</sup>
  - El impacto psicológico cambia con el tiempo
  - Las situaciones que se manejan en un principio pueden convertirse en problemáticas meses más tarde.
- El conocimiento adquirido en el hospital puede tornarse limitado en términos de su posibilidad de uso<sup>2</sup>
  - Los miembros de la familia experimentan nuevas dimensiones de la enfermedad.
  - Surgen nuevas situaciones y contextos, que aumentan el alcance de lo que se ha aprendido.





## Psychological Experience of Parents of Children With Type 1 Diabetes:

A Systematic Mixed-Studies Review

Robin Whittemore, PhD, APRN, FAAN, Sarah Jaser, PhD, Ariana Chao, MSN, Myoungock Jang, MSN, and Margaret Grey, DrPH, RN, FAAN  
Yale School of Nursing, New Haven, Connecticut

**Results**—The prevalence of parental psychological distress across all studies ranged from 10% to 74%, with an average of 33.5% of parents reporting distress at diagnosis and 19% of parents reporting distress 1 to 4 years after diagnosis. Parental psychological distress in parents of children with T1DM, regardless of how it was defined, was associated with higher child self-report of stress and depressive symptoms, more problematic child behavior, and lower child self-report of quality of life. Parental psychological distress also had negative effects on diabetes management. Themes of the qualitative synthesis indicated that parents perceived T1DM as a difficult diagnosis that contributed to significant family disruption. Adjustment occurred over time; however, ongoing stress was experienced.

**Conclusions**—Screening for psychological distress in parents of children with T1DM is indicated, and preventive interventions are needed.

El 33,5 % de los padres reportaron estrés al diagnóstico y el 19 % a lo largo de la evolución.



## Psychological Experience of Parents of Children With Type 1 Diabetes:

A Systematic Mixed-Studies Review

Robin Whittemore, PhD, APRN, FAAN, Sarah Jaser, PhD, Ariana Chao, MSN, Myoungock Jang, MSN, and Margaret Grey, DrPH, RN, FAAN  
Yale School of Nursing, New Haven, Connecticut

- **El estrés en los padres se asocia a:**
- Mayor alteración en la comunicación familiar
- Incremento de los conflictos
- Disminución de la efectividad de los padres como cuidadores
- Peor salud tanto emocional como física.





## **Psychological Experience of Parents of Children With Type 1 Diabetes:**

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Yale School of Nursing, New Haven, Connecticut

- **El estrés en los padres se asocia en los hijos a:**
- Mayor número de síntomas depresivos
- Trastornos de conducta
- Menor calidad de vida
- Peor control metabólico.



## Psychological Experience of Parents of Children With Type 1 Diabetes:

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- **Los síntomas depresivos se asociaron a:**
- Menor disciplina, menor presencia paterna y acompañamiento, menor adaptación y cohesión familiar y mayor número de conflictos.
- **La ansiedad parental :**
- Mayor control materno, sobreprotección y dificultad en la autonomía.



## Psychological Experience of Parents of Children With Type 1 Diabetes:

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Yale School of Nursing, New Haven, Connecticut

### Clinical Recommendations for Parents of Children With Type 1 Diabetes Mellitus

Assess parental stress, anxiety, and depression with a brief assessment form or in private consultation.

Stress—Pediatric Inventory for Parents<sup>61</sup>

Anxiety—State-Trait Anxiety Inventory (STAI)<sup>45</sup>

Depression

Center for Epidemiologic Studies-Depression (CES-D)<sup>62</sup>

Beck Depression Inventory (BDI)<sup>63</sup>

Brief Depression Screening Tool<sup>42</sup>

Anxiety and Depression

General Health Questionnaire (GHQ)<sup>64</sup>

Psychosocial Adjustment

Psychosocial Assessment Tool (PAT2)<sup>65</sup>

Identify high-risk parents such as single parents, those from minority groups, or those without social support.

Inform parents that stress and distress are common in parents of children with T1DM.

Encourage parents to actively seek support from family, friends, peers, and professionals.

Provide parents with Internet sources of peer support.

Refer parents with elevated symptoms of stress, anxiety, or depression to their primary care provider or a mental health professional.

Educate parents with elevated symptoms of stress, anxiety, or depression that their emotional status not only affects them negatively but also affects their child and family, thus reinforcing the importance of effective management.



RESEARCH

Open Access

## Assessment of psychosocial variables by parents of youth with type 1 diabetes mellitus

Fani Eta Korn Malerbi<sup>1\*</sup>, Carlos Antonio Negrato<sup>2</sup>, Marilia B Gomes<sup>3</sup> on behalf of the Brazilian Type 1 Diabetes Study Group (BrazDiab1SG)

### Abstract

**Purpose:** To evaluate the impact of type 1 diabetes (T1D) on family functioning and child-rearing practices from parents' point of view, to assess parents' health-related quality of life and to explore the relations between psychosocial variables and diabetes care outcomes in youth with diabetes.

**Methods:** This research was part of the cross-sectional multicenter Brazilian Type 1 Diabetes Study, conducted between December 2008 and December 2010 in 28 public clinics of 20 cities across four Brazilian geographical regions. Psychosocial questions **1,079** parents of patients with T1D<sub>low</sub> (89.3% mothers, 52.5% Caucasians) low socioeconomic levels. Parents were also submitted to health-related quality of life instruments (EQ-5D+EQ-VAS). Clinical data from the last medical appointment were collected by a physician using standardized chart review forms. The demographic, educational and socioeconomic profiles were also obtained and HbA1c levels registered.

(89.3% mothers, 52.5% Caucasians, 38.6 ± 7.6 years old). Overall, 72.5% of the families were from low or very low socioeconomic levels. Parents were also submitted to health-related quality of life instruments (EQ-5D+EQ-VAS).

the only parent involved in diabetes care in 50.9% of the cases. The majority of parents (70.9%) mentioned changes in family functioning after the diagnosis, although they neither treated their diabetic children differently from the others (76.3%), nor set prohibitions (69.1%) due to diabetes. The majority was worried about diabetes complications (96.4%) and felt overwhelmed by diabetes care (62.8%). Parents report of overwhelming was significantly associated with anxiety/depression, as measured by the EQ-5D questionnaire. Less than half of the patients had already slept over, and the permission to do it increased as a function of children's age. Nearly half of the parents (52%) admitted to experiencing difficulties in setting limits for their children/adolescents. HbA1c levels in patients from this group (9.7 ± 2.5%) were significantly higher than those of children/adolescents whose parents reported no difficulties towards limit-setting (8.8 ± 2.1%). Parents whose children/adolescents reported the occurrence of hypoglycemic episodes in the last month complained significantly more about anxiety/depression (55.1%) than parents from patients who did not report it (45.7%). Also a significantly greater proportion of parents whose children/adolescents had been hospitalized due to hyperglycemia reported anxiety /depression (58.7%) than those whose children/adolescents had not been hospitalized (49.8%).

**Conclusions:** After the diagnosis of T1D, the lifestyle of all family members changes, what interferes with their quality of life. Mothers are still the primary caregivers for children/adolescents with diabetes. Difficulty to set limits for children/adolescents may be a risk for poor metabolic control. The study demonstrates the importance of family context in the adjustment of young patients to T1D. The specific needs of T1D patients and their impact on a family routine must be considered for future improvement on therapy elements and strategies.

**Keywords:** Type 1 diabetes, Family functioning, Psychosocial variables, Diabetes in youth, Glycemic control

RESEARCH

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## Assessment of psychosocial variables by parents of youth with type 1 diabetes mellitus

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**Table 3 Number and percentage of parents' answers to questions focusing psychosocial aspects related to their children's diabetes**

Parents assertions	n (%)
Family functioning was modified by my child with diabetes	842 (78.5%)
After the diagnosis the relationship with my spouse changed	324 (31.6%)
There is always an adult (mother/father/grandparent/etc.) involved in diabetes care	1,041 (96.8%)
I do not treat my child with diabetes differently from my other children	781 (76.3%)
I do not set prohibitions to my child because he/she has diabetes	741 (69.1%)
The patient is encouraged to perform diabetes management tasks	978 (91.7%)
I am worried about diabetes complications	1,032 (96.4%)
I am worried about hypoglycemic episodes	1,005 (93.9%)
I'm afraid that diabetes develops in another sibling	706 (69.1%)
I have already checked my non-diabetic children's blood glucose	654 (64.2%)
I feel overwhelmed with caring for my child's diabetes	672 (62.8%)
My child has already slept over	440 (41.0%)
I have had difficulties in setting limits for my child with diabetes	555 (52.0%)

RESEARCH

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## Assessment of psychosocial variables by parents of youth with type 1 diabetes mellitus

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**Table 4 Number and percentage of parental answers reporting problems in the five health aspects of the EQ-5D questionnaire**

I do have problems with	Fathers+Mothers n (%)	Fathers n (%)	Mothers n (%)	P-Value
Mobility	77 (7.2%)	10 (8.8%)	67 (7.0%)	0.47
Self-care	19 (1.8%)	2 (1.8%)	17 (1.8%)	0.99
Usual activities	73 (6.8%)	7 (6.2%)	66 (6.9%)	0.78
Discomfort	385 (36.0%)	29 (25.7%)	356 (37.3%)	0.05
Anxiety/depression	547 (51.2%)	37 (32.7%)	510 (53.4%)	<0.001

Casi la mitad de las madres tenían ansiedad o depresión

# Factores puede contribuir al desarrollo del agotamiento

## Algunas factores internos/rasgos de personalidad:

- Expectativas idealistas del yo.
- Acción y compromiso con el punto de sobreestimación del yo y de sentir una sobrecarga.
- Supresión de las necesidades propias.
- Sentimiento de ser irremplazable y de no querer delegar.

## Algunos factores externos:

- Grandes demandas de tareas a realizar.
- Falta de libertad para la toma de decisiones
- Mayores responsabilidades
- Ausencia de apoyo social
- Instrucciones contradictorias
- Falta de un comentario positivo
- Falta de recursos

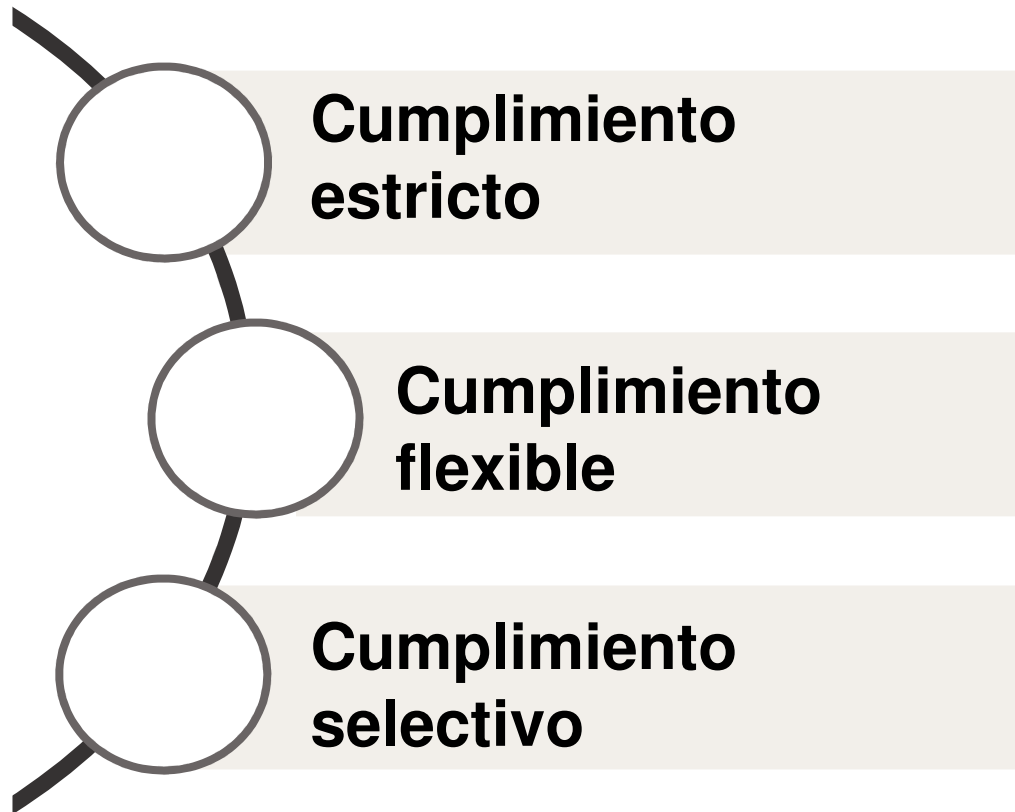


## Communicating With Children and Families: From Everyday Interactions to Skill in Conveying Distressing Information

- Los padres necesitan conocimientos, acompañamiento y contacto con otras familias en situación similar.
- Son parte esencial del proceso terapéutico y es importante que sus consideraciones y puntos de visita sean tenidos en cuenta.
- Hacerlos sentir expertos y los profesionales sus asesores.
- El médico será empático, honesto y bien informado fuente de fortaleza para los cuidadores.



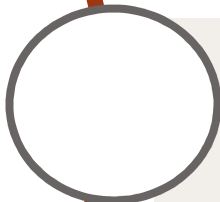
Tres abordajes que los padres pueden utilizar para manejar el cuidado de la diabetes tipo 1 de su hijo



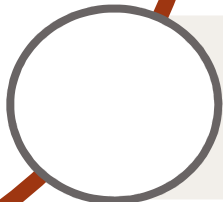
Tres abordajes que los padres pueden utilizar para manejar el cuidado de la diabetes tipo 1 de su hijo



## Cumplimiento estricto



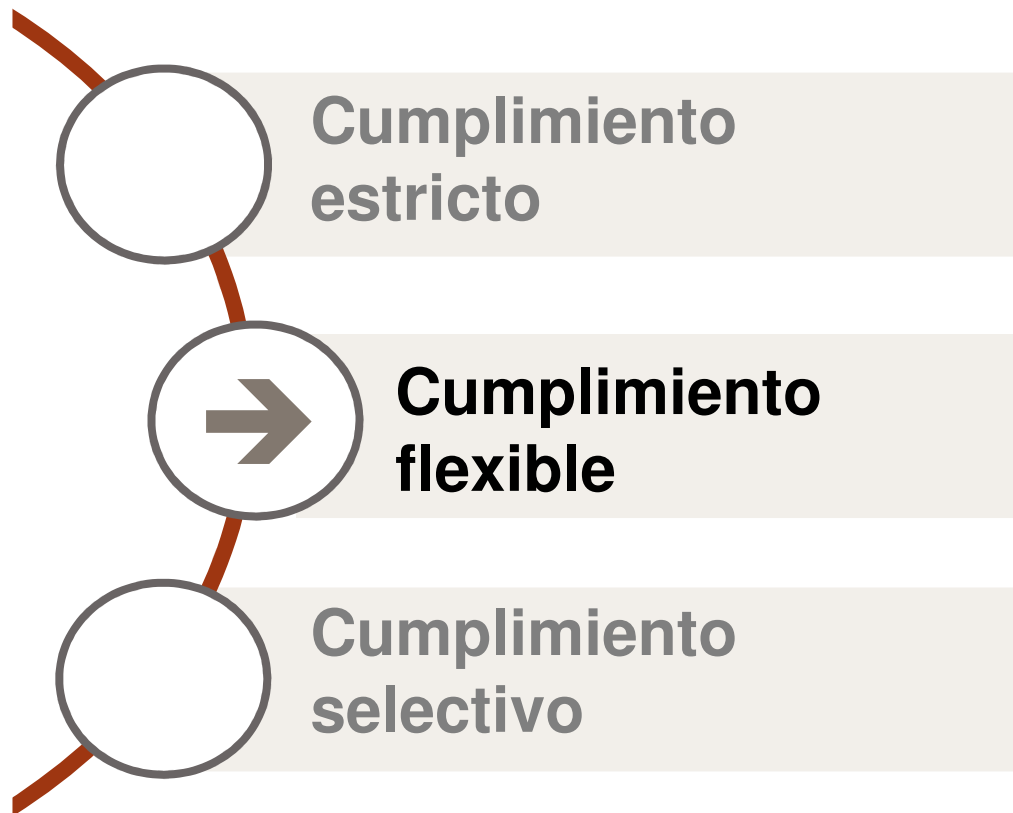
## Cumplimiento flexible



## Cumplimiento selectivo

- Un estilo de manejo estricto es el que generalmente se adopta después del diagnóstico de diabetes tipo 1.
- Los padres cuidan a sus hijos como vigilantes, en gran medida por los temores (p. ej., hipoglucemia, complicaciones a largo plazo).
- Los padres se colocan a sí mismos bajo la gran presión de hacer un buen trabajo.
- Las madres pueden hacer una pausa en sus carreras para concentrarse en el cuidado.
- Los padres tienden a mantenerse dentro del ambiente del hogar: buscan la familiaridad

Tres abordajes que los padres pueden utilizar para manejar el cuidado de la diabetes tipo 1 de su hijo



- Los padres generalmente avanzan hacia este estilo de manejo 6-12 meses después del diagnóstico de diabetes tipo 1.
- El cambio indica un avance en la confianza.
- Los padres se muestran proclives a modificar el regimen de tratamiento para:
  - Hacer que la vida sea más vivible.
  - Manejar mejor los desafíos normales
- Este abordaje implica el uso de ensayo y error para aprender cómo manejarse.

## Momento de reforzar la educación Puede aparecer tristeza o depresión

Tres abordajes que los padres pueden utilizar para manejar el cuidado de la diabetes tipo 1 de su hijo



**Cumplimiento  
estricto**



**Cumplimiento  
flexible**

**Cumplimiento  
selectivo**

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Tres abordajes que los padres pueden utilizar para manejar el cuidado de la diabetes tipo 1 de su hijo

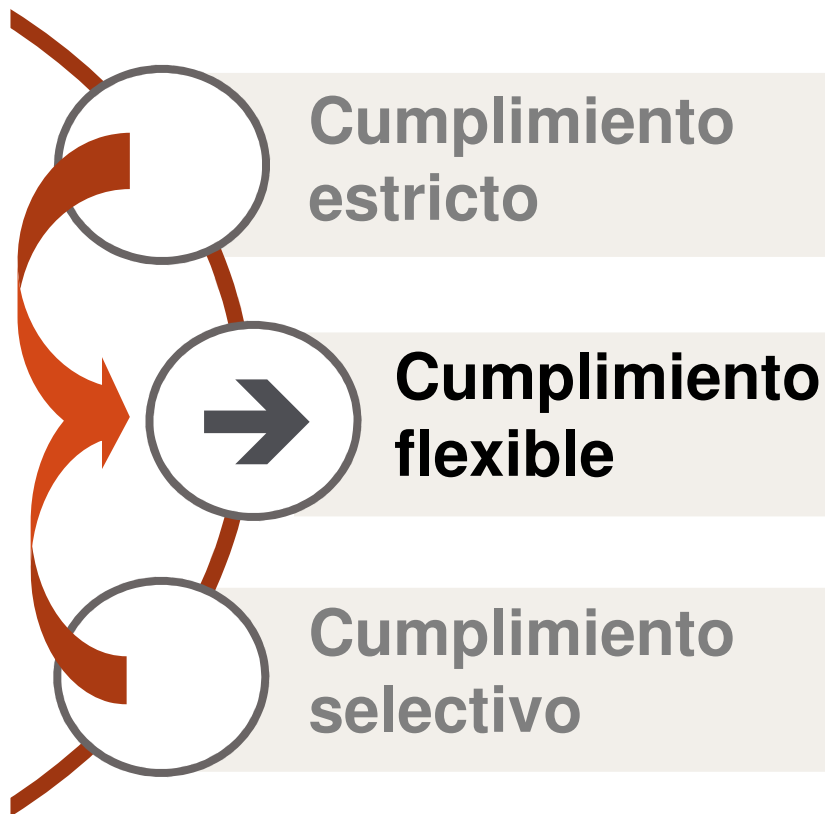


**Cumplimiento  
estricto**

**Cumplimiento  
flexible**

**Cumplimiento  
selectivo**

- Los padres pueden ser selectivos con respecto a su foco de concentración.
  - Ocasionalmente pueden utilizar una conducta de manejo extremo para intentar y manejar mejor la diabetes tipo 1 de su hijo.
  - Pueden esconder al profesional de la salud cómo se sienten o manejan la enfermedad en el hogar.



### Recomendaciones

- Brindar:
  - Información.
  - Apoyo con afirmaciones positivas
  - Apoyo emocional
  - Atmósfera de no juicio
  - Elogiar el trabajo realizado
- Escapar de las categorías de familias “que cumplen” vs. familias “que no cumplen”.
- Crear asociaciones con familias que desarrollan objetivos colaborativos y realistas.
- Ayudar a los cuidadores a identificar estrategias alternativas para lidiar con sus temores y construir confianza.

# Fathers' Reflections on Parenting Young Children With Type 1 Diabetes



- Las sensaciones iniciales fueron similares a las de las madres
- La preocupación de los padres tendían a tener que ver con el futuro y las de las madres con lo inmediato.

# Los hermanos

- La evidencia muestra que los ajustes de los hermanos y de los padres están interrelacionados.<sup>1</sup>
- Se ha demostrado que los hermanos de niños con condiciones crónicas se encuentran en mayor riesgo de problemas emocionales y de comportamiento.<sup>2</sup>

Los factores asociados con un peor ajuste de los hermanos incluyen<sup>2</sup>:

- Mayor edad del hermano en el momento del diagnóstico.
- Mayores niveles de estrés de los padres.
- Temperamento más difícil del hermano.
- Peor ajuste del niño con diabetes tipo 1.
- Percepciones más negativas del hermano respecto de la diabetes y su impacto en la familia.

**Simplemente preguntar a los padres por el hermano sano puede iniciar una conversación necesaria.<sup>1</sup>**



## Algunos sentimientos que pueden favorecer el Agotamiento

- Amenaza continua de castigo
- Temor al error terapéutico
- Perdida de la espontaneidad
- Vigilancia continua ( el control es el centro)
- Restricción de la actividad social
- Sensacion de caminar entre precipicios.

# La línea del tiempo



# Los niños pequeños

- La carga y el estrés de los cuidadores pueden ser más pronunciados cuanto menor es el niño con diabetes tipo 1.<sup>1</sup>
  - Los niños en la primera infancia tienen capacidad limitada de reconocer los síntomas, comunicar, razonar<sup>2</sup> y de automanejo.<sup>3</sup>
  - La mayor parte de la responsabilidad de las tareas relacionadas con la diabetes deben ser asumidas por el cuidador.<sup>4</sup>
  - Los niños en la primera infancia se encuentran en mayor riesgo de presentar hipoglucemia nocturna.<sup>4</sup>
  - La presentación de CAD puede ser de hasta el 37% en los niños en la primera infancia con diabetes tipo 1.<sup>2</sup>



# Los niños pequeños

-La Diabetes en un niño pequeño genera una marcada ansiedad familiar.

Situaciones que generan ansiedad:

- Sociedad poco familiarizada con la diabetes en niños tan pequeños.
  - Rutina de vida erráticas y dificultad para generar hábitos.
  - Compromiso extremo de las madres en el cuidado:
- Lange y Danne evaluaron el impacto económico y social de la diabetes en 580 familias con niños menores de 14 años.
  - Concluyeron que existía impacto económico y menor desarrollo laboral particularmente en las madres y en especial de niños con diagnóstico antes de los 6 años de edad.<sup>1</sup>



# Los niños pequeños

Estrategias prácticas que pueden ayudarle a asistir a los cuidadores.

- Asegurar que la educación sobre la diabetes incluya evaluaciones periódicas del estrés de las familias<sup>1</sup>
- Reconocer el estrés percibido, incluso en los padres de niños en la primera infancia con niveles de HbA<sub>1c</sub> dentro del rango objetivo.

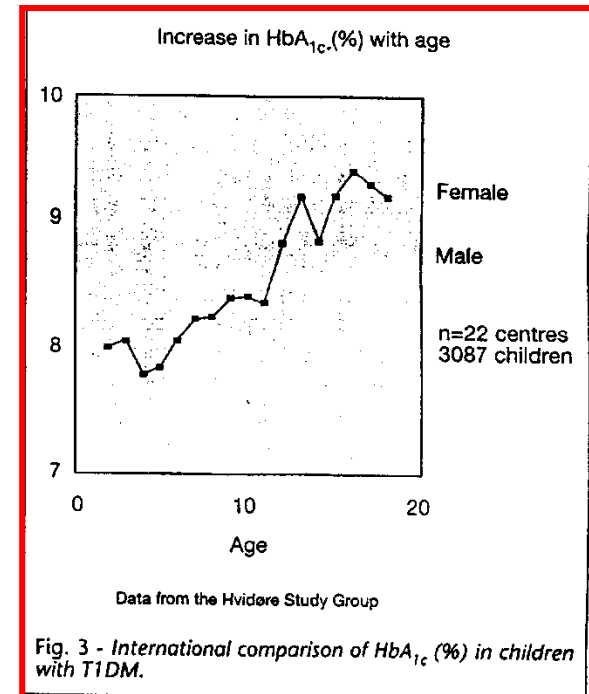


Fig. 3 - International comparison of HbA<sub>1c</sub> (%) in children with T1DM.

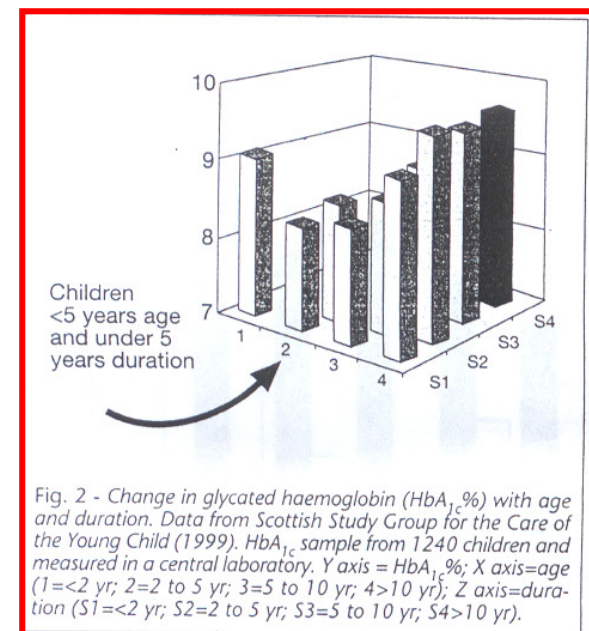


Fig. 2 - Change in glycosylated haemoglobin (HbA<sub>1c</sub>, %) with age and duration. Data from Scottish Study Group for the Care of the Young Child (1999). HbA<sub>1c</sub> sample from 1240 children and measured in a central laboratory. Y axis = HbA<sub>1c</sub>, %; X axis = age (1 = <2 yr; 2 = 2 to 5 yr; 3 = 5 to 10 yr; 4 >10 yr); Z axis = duration (S1 = <2 yr; S2 = 2 to 5 yr; S3 = 5 to 10 yr; S4 >10 yr).



### Recomendaciones para ayudar a reducir el estrés nocturno

- ❑ Ayudar a los padres a comprender mejor cómo reconocer los patrones de la glucemia nocturna.
- ❑ Evaluar periódicamente la frecuencia de los monitoreos nocturnos.
- ❑ Preguntar si el niño duerme solo.
- ❑ Informar a los padres sobre la disminución del riesgo de hipoglucemias utilizando adecuadamente basal bolo o infusión continua de insulina.

#### INV16 - Parenting a toddler with diabetes

J. Ivancsik<sup>1</sup>

<sup>1</sup>*The Children's Hospital at Westmead, Institute of Endocrinology and Diabetes, Westmead, Australia*

Healthcare professionals play an important role in shaping the way parents think about their child with diabetes. This presentation will integrate current literature, clinical practice wisdom and caregivers' experiences to explore the impact of parenting on health outcomes and psychological adjustment to diabetes.

Research suggests that the diagnosis of diabetes is a crucial variable that influences parent's psychological wellbeing and their ability to parent. Due to the pace of growth in infancy and toddlerhood (0-3 year olds), children have more rapid changes in development and behaviour than at any other stage of childhood. Therefore the treatment and management of diabetes in infants and toddlers pose unique challenges for their caregivers and healthcare professionals alike.

Post the diagnosis of diabetes parents are faced with the complex task of balancing competing needs and demands to achieve optimal glycaemic control and quality of life for their child. Carers of toddlers often struggle to adjust their parenting approach to keep normality in their child's life in a way that promotes positive physical, cognitive and emotional development, while integrating the day-to-day management of diabetes. Parents of toddlers with diabetes report higher parenting stress as well as higher levels of anxiety and fear associated with managing the condition, in particular fear of hypoglycaemia. These diabetes-specific worries and anxieties often lead to maladaptive coping strategies, such as over-protective parenting, which is shown to increase child-perceived vulnerability. This sense of vulnerability has been linked with an increased risk of depression and anxiety later in life.

Social Work can provide early intervention and support for parents with a toddler with diabetes which may be the key to establishing a solid parental framework; this is created through parent education, counselling and a multidisciplinary approach.

# Crisis adolescente en el contexto de la Diabetes.



- Egocentrismo.
- Importancia del aquí y ahora.
- Falta de conflicto en relación a la brecha generacional.
- Las consignas no son claras.
- La autoridad de los padres como modelo está cuestionada.
- El futuro es incierto.

# Factores que influyen en el deterioro del control glucémico y aumentan el riesgo de complicaciones

- Deseo de no ser diferente a sus pares.
- Adicciones “recreativas”.
- Baja autoestima.
- Depresión.
- El abandono de la consulta.
- Trastornos de la conducta alimentaria.

Lee P Diabet Med. 2009 26(4):328-333.

Dunger D. Diabetes Care. 2003;26:1052-1057.

Peveler R. Diabetes Care. 2005 28(1):84-88.

Bryden K. Diabetes Care.2001;24:1540-1536.

Pediatric Diabetes 2014: 15(Suppl. 20): 245–256.





# El agotamiento de los padres.

- Los padres de adolescentes pueden comenzar a descomprometerse prematuramente, generando:
  - Relaciones familiares tensas
    - Falta de supervisión de los padres en el manejo de la diabetes .
  - La transferencia de las tareas de cuidado relacionadas con la diabetes a los adolescentes antes de que estén completamente listos y sean capaces de aceptar la responsabilidad.<sup>1</sup>



1. Carcone AI, et al. *J Dev Behav Pediatr.* 2012;33(4):343-351.

## El conflicto padre-adolescente puede surgir a medida que los adolescentes avanzan hacia una mayor autonomía

- Los padres deben enfrentar:
  - Un cambio en el papel que juegan en la vida de su hijo
  - Los hijos pueden considerarlos “molestos” y “fastidiosos”.

Los métodos de los padres pueden exacerbar el conflicto con el niño adolescente mediante:

- La vigilancia<sup>1</sup>
- El control psicológico<sup>2,3</sup>
- El control inadecuado de la conducta<sup>3</sup>

## La familia puede tener dos tipos extremos de adaptación

- **Compromiso excesivo:**

Solo se habla y vive para la enfermedad

- **Desapego general:**

Solo una persona se hace cargo creandose una dependencia masiva; cuando el joven se independiza el cuidador queda sin rol.

# El estrés, el agotamiento y la reacción de huida.

- Abandono
- Muerte

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## CLUSTERING OF PREMATURE MORTALITY IN 1,761 INSULIN-DEPENDENT DIABETICS AND THEIR FAMILY MEMBERS

JILL M. NORRIS,<sup>1</sup> JANICE S. DORMAN,<sup>1</sup> RONALD E. LAPORTE,<sup>1</sup>  
MARIAN REWERS,<sup>1</sup> JEFFREY A. GAVARD,<sup>1</sup> TREVOR J. ORCHARD,<sup>1</sup>  
DOROTHY J. BECKER,<sup>2</sup> ALLAN L. DRASH,<sup>3</sup> AND LEWIS H. KULLER<sup>1</sup>

Cohorte de 1781 pacientes el 5 % de las madres y el 13 % de los padres habian fallecido.

Las causas mas frecuentes fueron enfermedad cardiovascular y cancer.

Comparando padres de hijos fallecidos /padres de hijos vivos la mortalidad era de 18 vs 8% a la edad de 55 años.



AMBOS SEXOS

JURISDICCION	TOTAL	0-4	5-9	10-14	15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80 y más
<b>Total del país</b>	<b>40.518.391</b>	<b>3.419.673</b>	<b>3.321.992</b>	<b>3.414.646</b>	<b>3.449.559</b>	<b>3.349.723</b>	<b>3.209.903</b>	<b>3.248.807</b>	<b>2.712.018</b>	<b>2.373.257</b>	<b>2.225.891</b>	<b>2.068.656</b>	<b>1.903.397</b>	<b>1.627.136</b>	<b>1.329.074</b>	<b>1.071.331</b>	<b>845.028</b>	<b>948.896</b>
Ciudad Autónoma de Buenos Aires	3.059.309	199.698	204.003	176.958	180.270	200.745	231.834	256.213	229.298	196.981	182.357	174.466	166.614	154.849	138.913	118.120	100.829	146.872
Catamarca	404.240	43.281	40.298	39.773	38.967	34.497	31.280	30.862	26.078	22.119	19.931	18.363	16.338	12.967	9.842	7.714	5.985	5.925

TABLA D1. DEFUNCIONES SEGURIDAD SOCIAL POR JURISDICCION DE RESIDENCIA Y SEXO - REPUBLICA ARGENTINA - AÑO 2010

JURISDICCION DE RESIDENCIA	20-29	30-39	40-49	50-59	60-69	70-79	80 y más	Total
<b>REPUBLICA ARGENTINA</b>	<b>1.247</b>	<b>1.372</b>	<b>1.438</b>	<b>1.523</b>	<b>1.449</b>	<b>1.189</b>	<b>823</b>	<b>12.290</b>
Capital Federal	176	229	255	293	329	309	239	2.030
Buenos Aires	1.071	1.143	1.183	1.230	1.120	880	584	10.260
Córdoba	36	21	20	45	66	75	198	340

SECRETARIA DE POLITICAS, REGULACION E INSTITUTOS  
DIRECCION DE ESTADISTICAS E INFORMACION DE SALUD

La mortalidad es 9 veces mayor a predominio materno.

**Poblacion general CABA Buenos Aires**

25-45 a	Total	Varones	Mujeres
Poblacion	5.385.318	2.685.418	2.699.900
Mortalidad	7.671	4.979	2.680
% Mortalidad	0,14	0,18	0,099

**Padres HGNPE. N:600**

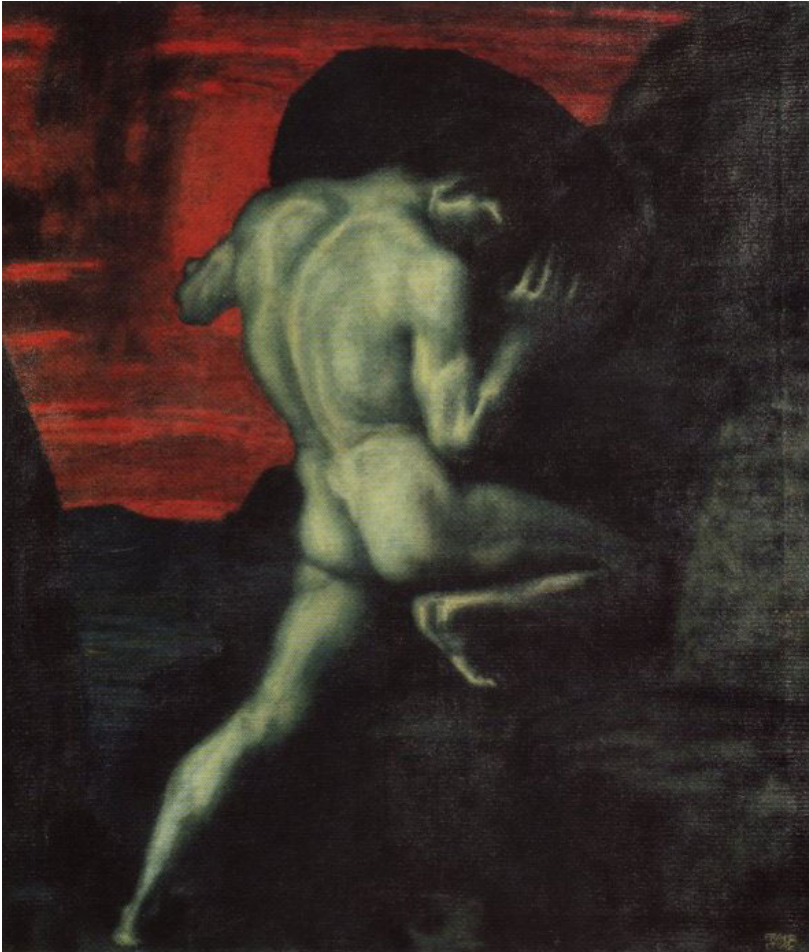
25-45 a	Total	Varones	Mujeres
Poblacion	1200	600	600
Mortalidad	13	5	8
% Mortalidad	1,08	0,8	1,3

Padres: 3 Infartos 2 Accidentes  
Madres :7 Tumores 1 Desconocida.

- *Cuando el paciente y la diabetes se convierten en el epicentro familiar aparecen sentimientos de compasión, lastima, desamparo, sobreproteccion, impotencia y sus contracaras.*

*Los sentimientos circulan entre el niño, padres , hermanos.*

*La capacidad de adaptacion y afrontamiento de la familia depende de sus propios recursos*



*No eludir el conflicto.  
Acompañar el proceso que es diferente para  
cada persona, familia y cultura.  
Mantener la individualidad y favorecer la  
autonomía.*