Coping strategies for managing a child with complex medical needs

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Congenital hyperinsulinism

- Pediatric illness
- Rare disease
- Chronic illness
Pediatric illness

- Children are developing:
  - They are changing and growing

- Children are vulnerable:
  - They are not able to speak or express themselves
  - They are not aware of what they need
  - They can not take care of themselves

- Parents have to take care of the child:
  - The parents’ role versus the carers’ role
  - They must make decisions on medical or surgical treatment for their child
  - Sometimes have to face a lethal or disabling condition

THE DISEASE NOT ONLY AFFECTS THE INDIVIDUAL, IT AFFECTS THE WHOLE FAMILY

Rare disease

- It is an uncommon and little is known about it
- There are fewer resources and they are less specialized:
  - The care for parents is more complicated
  - The life for these children is more difficult
    - Growing
    - Hospitals
    - Treatment
    - Play
    - Nursery-school/School
    - Sport
    - Social relationships
- Stigma → Social isolation

THE IMPORTANCE OF THE PARENTS’ ASSOCIATIONS IN THESE LITTLE KNOWN DISEASE CAN BE A SUPPORT FOR THE PARENTS AND THE CHILDREN

Chronic illness

- Permanent or residual disability
- Irreversible pathological changes
- It requires continuous monitoring, observation, care and rehabilitation
- Families need to adapt to chronic disease:
  - Diagnosis
  - Day after day
  - Long term consequences
- Parents of children with chronic disease:
  - Are the most affected with the diagnosis
  - They can never take a break
  - Could be overburdened with management and caring of the child

CHILD AND PARENTS HAVE TO MAKE LONG TERM CHANGES IN THEIR LIVES

FAMILY MEDICAL TEAM

- Give information
- Support

FAMILY

- Carers
- Expectations
- Feelings
- Family ties

Body and life impact

PATIENT

Course Childhood adversities. M Albert. Psychiatry and Psychology department, Hospital Sant Joan de Déu, Barcelona
Grieving for the healthy child

• Kübler-Ross Model

Five stages of grief:
  • Denial
  • Anger
  • Bargaining
  • Depression
  • Acceptance

Course Childhood adversities. Marta Albert. Psychiatry and Psychology department, Hospital Sant Joan de Déu, Barcelona
Parents

- May exhibit emotional and psychological symptoms such as:
  - Sadness
  - Guilt
  - Anger
  - Feeling of powerlessness
  - Anxiety
  - Fear
  - Insecurity
  - Loss of self-esteem
  - Somatic symptoms: pain, feeling unwell...

Parents

• These symptoms can interfere:
  • Parents level of understanding → Adherence to treatment
  • Negatively influence the behavior of the child
  • Affect the prognosis

• And...
  • Their health and lives!

PARENTS HAVE A HIGHER RISK OF DEVELOPING MENTAL ILLNESS

Warning signs!!

- If symptoms continue for longer than six months
- Greater discomfort than expected
- Significant impairment to occupational activity
- Feeling guilt or worthlessness
- Thoughts of death
- Weight loss
- Insomnia

Resilience

• A set of social and personal processes that enables people to adapt well physically and psychologically, despite adversity

• Family resilience (Walsh, 1996):
  – Processes of adaptation and adjustment of family to demands of illness
  – It is essential to maintain a good quality of life for children and their family
  – A family with resilience is able to mobilize its resources and use support systems
  – It depends on:
    • The sick child: reactions, emotions, symptoms...
    • Disease: stage, course, severity...
    • Family: culture, organization, communication...
    • Contexts: employment, health...

• Professionals can help families develop resilience

Resilience

- Multi-dimensional intervention model:
  - Centered on the family’s characteristics and specific needs
  - Knowledge of the disease and troubleshooting
  - The support available in their environment
  - The development of capacities and resilience

- Multi-disciplinary team:
  - Doctor
  - Nurse
  - Social Worker
  - Mental health professional:
    - Psychological therapy: individual/group
    - Drugs

Strategies for parents

- Learn about the illness
- Talk about questions and concerns
- Seek support from family, friends, other affected families, professionals...
- Accept offers of help by friends and family
- Recognize psychological or behavioral changes
- Take care of yourself: eat well, sport, sleep...
- Breathing and relaxation techniques, yoga
- If possible go to work
- Take each day one day at a time
- Don’t compare your life to others
- Don’t try to be a perfect person

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Strategies for children

• If it’s possible maintain daily routines
• Teach children about the illness
• Encourage children to participate in their care and treatment
• Talk with the child: use simple language
  – Reassure children, ensure they do not feel guilty
  – Explain that you understand how difficult the situation can be
• Recognize psychological or behavioral changes
• Do not judge their feelings
• Relaxation techniques

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Relaxation session

- Deep breathing:
  - Sit comfortably
  - Put one hand on your stomach
  - Close your eyes
  - Breath in through the nose (5s)
  - Hold the breath (5s)
  - Breath out through the nose or mouth (10s)
  - Repeat five times

THANK YOU FOR YOUR ATTENTION!!!