EDUTOUR:
A NEW PSYCO-EDUCATIONAL PROGRAMME FOR TOURETTE'S SYNDROME SUFFERERS AND THEIR FAMILIES

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Spanish Tourette Syndrome Association (APTT).
INTRODUCTION

• Tourette syndrome (TS) is a neurological disorder characterized by motor and vocal tics.
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TICS

Tics are movements (motor tics) or vocalizations or sounds (phonic or vocal tics) involuntary, sudden, quick, recurrent arrhythmic and stereotyped.

1. SIMPLE
   Usually affect a single muscle group

2. COMPLEX
   Sequential movement patterns in different parts of the body involving various muscle groups, or complex sounds
TICS CLASSIFICATION EXAMPLES.

<table>
<thead>
<tr>
<th>Simple tics</th>
<th>Complex tics</th>
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<tbody>
<tr>
<td>✓ Simple motor tics:</td>
<td>✓ Complex motor tics:</td>
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<tr>
<td>✓ Closing of eyes</td>
<td>✓ Smelling objects</td>
</tr>
<tr>
<td>✓ Neck jerking</td>
<td>✓ Jumping</td>
</tr>
<tr>
<td>✓ Shrugging</td>
<td>✓ Touching</td>
</tr>
<tr>
<td>✓ Facial gestures</td>
<td>✓ Echopraxia</td>
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<td>✓ Simple vocal tics:</td>
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<tr>
<td>✓ Coughing</td>
<td>✓ Repeating words or phrases</td>
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<tr>
<td>✓ Hawking</td>
<td>✓ out of context</td>
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<tr>
<td>✓ Growling</td>
<td>✓ Coprolalia</td>
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<tr>
<td>✓ Deep inhaling through the nose</td>
<td>✓ Palilalia</td>
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<td>✓ Blowing</td>
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TOURETTE SYNDROME.

SYMPTOMS

• Motor and vocal tics (100%)

• Patients have other associated disorders:
  – attention deficit / hyperactivity disorder (TDAH) (80%)
  – obsessive-compulsive disorder (60%)
  – Behavioral, learning and psychopathology problems, such as depression or anxiety.

• Quality of life affected
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PSYCHOEDUCATION
EDUPARK PROGRAM.
PSYCHO-EDUCATIONAL PROGRAM FOR TOURETTE'S SYNDROME SUFFERERS AND THEIR FAMILIES

“Edutour” is based on the Edupark program with the support from the European Commission.

“Edutour” is developed with the support of a grant from Fundación "La Caixa" on 2006

EduPark program:
Psychoeducational Program for patients with Parkinson's disease
Project Nº: QLK6-CT-2002-02674
“Quality of Life and Management of Living Resources

Edutour program authors:
Anna Prats, Àngels Bayés, Mari Cruz Crespo, Clara López
PROCEDURES

- **Phase I:** Exploration of psycho-social needs of those affected by TS and caregivers through a homemade survey.

- **Phase II:** EduPark program adaptation for children (EduTour) and adolescents affected by TS (e-Tour) and their families.

- **Phase III:** EduTour/e-Tour implementation to pilot groups (family and patients in parallel groups).

- **Phase IV:** Psychosocial evaluation and satisfaction questionnaire. Evaluation of clinical changes.
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Phase I: Exploration of psycho-social needs of those affected by TS and caregivers through a homemade survey.

- **Subjects:** Affected by TS from the Spanish Association for Tics and Tourette Syndrome (APTT) and their families.

- **Instruments:** Specific survey for the study of the psychosocial needs of TS designed by Parkinson Teknon Unit.

- **Procedure:** Survey was sent to those affected and their families. Analyzed using the SPSS / WIN (V12.0) for descriptive analysis.
PROCEDURES

Phase I: Exploration of psycho-social needs of those affected by TS and caregivers through a homemade survey.

- 36 families are surveyed.
- 91% are mothers / fathers.
- Identified as most worrying: anxiety disorders (63%), obsessions (51%), attention deficit and behavioral disorders (49%).
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Phase II: EduPark program adaptation for children (EduTour) and teenagers (e-Tour), affected by TS and their families.

OBJECTIVES

• To increase the understanding of the disease

• To provide knowledge and self-management skills to:
  - Prevent, control and reduce emotional stress generated by TS.
  - Develop special skills to interact with TS sufferer.

• To improve quality of life
Phase II: EduPark program adaptation for children (EduTour) and teenagers affected by TS (e-Tour) and their families.
## PROCEDURES

**Phase II:** EduPark program adaptation. **KEY COMPONENTS**

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<th>RELATIVES</th>
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PROCEDURES

Phase II: EduPark program adaptation. SESSION ELEMENTS

Sessions elements

- General scheme
- Tasks discussion
- Active Information
- Exercises
- Homework
- Preparation week
- Material

Review of homework from previous session

Knowledge

Skill practice and discussion

Exercises to practice skills and knowledge

Activities to prepare next session at home

Written material
## PROCEDURES

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Exemple: Session 8: RELATIVES

Homework discussion: STRESS MANAGEMENT (25 min)
  - Advanced level: Testing alternative thought.
  - Basic level: Daily relaxation training.

Active information: CAREGIVER CHALLENGE: TAKING CARE OF ONESELF (30min)
  - Definition: Have you noticed a problem with your health/life as a result of dealing with Tourette syndrome? Do you maintain your leisure activities?
  - The importance of recognize the caregiver distress and practice enjoyable activities.
  - Guide: How to maintain wellness and recognize caregiver distress? What is essential to carry out leisure activities?

Exercises: PREVENTING HEALTH PROBLEMS RELATED TO CARING (20min)
  - Advanced level: Reflexion on caring experience
  - Basic level: Nice objects exploration.

Homework: THE EXPERIENCE OF CARING (10 min)
  - Advanced level: Write a diary about experience of caring
  - Basic level: Do a new enjoyable activity every day.

Aperitif: SOCIAL SUPPORT (5 min)
  - Participants have to think about the help that they would like to receive (relative, friends, neighbours, partnerships, paediatricians, neurologists, etc.).
Exemple: Session 8: KIDS (8-12)

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- **Homework discussion:** GOING TO RELAX (20 min)
  - Detect when we are tense and practice an activity that relaxes us.

- **Active information:** SELF-ESTEEM (20min)
  - Discussion of the previous day’s aperitif: Find three adjectives that describe it.
  - Reading story to discuss self-esteem: What is it? What’s the point? How to improve it?

- **Exercises:** Games to encourage self-esteem (20min)

- **Homework:** Ask three people in our environment to describes us in five words.

- **Aperitif:** MAKING FRIENDS (5min)
  - What do you do when you want to make a new friend?

- **Session’s assessment:** Distribution of faces on RECORD CARDS PROGRAM. (10min)
Exemple: Session 8: TEENAGERS (13-18)

- **Homework discussion**: HEALTHY HABITS (20 min)
  - Make a schedule of healthy habits.

- **Active information**: SELF-ESTEEM (20 min)
  - What is it? What’s the point? How to improve it?

- **Exercises**: (20 min)
  - Viewing movie cuts (*Front Of The Class: How Tourette Syndrome Made Me the Teacher I Never Had*)
  - Self-esteem discussion

- **Homework**: IMAGINE YOURSELF
  - Imagine how you are going to be in ten years.

- **Aperitif**: FRIENDS (5 min)
  - Think about your group of friends and describe it in five words.

- **Session’s assessment**: (10 min)
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• **Phase IV:** Psychosocial evaluation of the psycho-educational program and satisfaction questionnaire, evaluation of clinical changes and psychosocial needs.
3 pilot studies to assess the acceptance and satisfaction of the program by children and teenagers and their families.

- Mars-April 2009: 5 kids, 12 adults
- Nov 2009: 7 kids, 11 adults
- Mars 2011: 4 teenagers, 6 adults
100% of participants responded affirmatively when asked:

- I have received useful information about the TS and about the potential psychosocial problems that can be associated with the disease.
- The program has helped me to understand that I am not alone with my problems.
- I think I'm more prepared to deal with the problems related to TS.
- The atmosphere in the group has been nice and I felt comfortable.
- I would participate in another program with similar characteristics.
- I would recommend this program.

83% responded affirmatively when asked:

- Generally, this program has reached my expectations.
- The program was the right for me.

67% responded affirmatively to the following statement:

- My understanding of the TS and the problems associated with the disease has improved.
PROCEDURES
Phase III & IV: Implementation and evaluation of the program
PATIENTS with TS (8-14 years)

100% of patients responded affirmatively when asked:
- I've learned about my illness.
- I liked to participate in the program.
- The exchange of ideas and experiences with others has helped me.
- The program has helped me to understand that I am not alone with my problems.
- I think now I'm more prepared to deal with the problems of the disease.
- I had fun.
- The program was the right for me.
- If you did a similar program I'd like to come.
- I would recommend it to other children with tics.
**PROCEDURES**

**Phase III & IV: Implementation and evaluation of clinical changes**

**Patients with TS (8-14 years)**

Anxiety (CMAS) and depression (CDI) assessment to patients & family members (HAD).

No significant changes (Wilcoxon Test NPar t > 0.05).

- Weak points: No control group. Small sample.
- Further studies are needed with broader samples.
Decreased anxiety in children (8-13) with TS after implementation of the “Edutour” program
CONCLUSION

• The psycho-educational program EduTour can be a useful psychosocial resource for those affected by Tourette syndrome and their families.

• Teenager Tourette Syndrome sufferers and their families need a program adapted to their needs such as e-Tour.

• Studies to demonstrate its effectiveness and efficiency are needed.

• Effectiveness should be corroborated with a larger sample.
Thank you very much for your attention!!!

- Angels Bayés, Neurólogo
- Francesc Miquel, Neurólogo
- Sheila Alcaine, Fisioterapia
- Cristina Petit, Logopedia
- Mercé Casanovas, Logopedia
- Mari Cruz Crespo, Psicologia
- Anna Prats, Neuropsicología
- M. Garolera, Neuropsicología
- A. Holtohefer, T. Ocupacional
- Paola Quispe, Secretaria

- Lluisa Aran, Coordinadora ejecutiva
- Dra. Àngels Bayés Rusiñol, Neurología. Dirección

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