Effects of psychoeducational intervention and teleassistance in children and adolescents with neuromuscular diseases

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Index

- Introduction
- Aims
- Sample research
- Methodology
- Results
- Conclusions
The neuromuscular diseases are genetic character affections, generally hereditary, which fundamental symptoms are the atrophy and the muscular weakness.

Among these, a wide type are the miopatias, where there are Steiner’s, Becker’s, waist dystrophy, etc. The muscular dystrophy of Duchenne is the most common neuromuscular disease in the childhood.

In a symptomatic level, the muscular affectation is very vast.
Frequently problems of depression and anxiety occur, these are related with the uncertainty and the progressive loses.

To go through the mourning process usually entails a progressive social isolation related to mobility problems.

The lack of communication and interaction with peers produce an increase of stress levels, of solitude feelings, defencelessness and helplessness.
# Background

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Title</th>
<th>Main results</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Savolainen et al. (2008)</td>
<td>An Internet-based videoconferencing system for supporting frail elderly people and their carers</td>
<td>88% of the participants reported that the system very much reduced their sense of loneliness and isolation</td>
</tr>
<tr>
<td>2. Germain et al. (2009)</td>
<td>Effectiveness of Cognitive Behavioural Therapy Administered by Videoconference for Posttraumatic Stress Disorder</td>
<td>No significant difference in the effectiveness of the videoconferencing and face-to-face condition</td>
</tr>
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## Background

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<tr>
<td>4. Raggi et al. (2010)</td>
<td>Concordance between severity of disease, disability and health-related quality of life in Myasthenia gravis</td>
<td>Results confirm a significant relationship between MG severity groups, HRQoL and disability profiles</td>
</tr>
<tr>
<td>5. Boosman et al. (2011)</td>
<td>Evaluation of change in fatigue, self-efficacy and health-related quality of life, after a group educational intervention programme for persons with neuromuscular diseases or multiple sclerosis: a pilot study</td>
<td>This pilot-study provides preliminary evidence for the effectiveness of a group educational intervention in improving HRQoL without increasing fatigue in person with NMD and MS</td>
</tr>
</tbody>
</table>

Extracted from: 4. Neurological Sciences, 5. Disability and Rehabilitation
Myasthenia Gravis
Limb-girdle Muscular Dystrophy
Becker Muscular Dystrophy
Facioscapulohumeral Muscular Dystrophy

- Rare diseases
- Low prevalence
- Chronic diseases
- Similar symptoms
- Physically disabling

- Geographic dispersion
- Rural areas
- Feeling of isolation
- Dependence
- High health care costs
Aims

Create a Website

Improve HQoL levels

Reduce health care costs

Reduce feeling of isolation
The main aims of this study were:

- to evaluate the effectiveness of an online program for the development and the enforcement of self-esteem, social skills, problems solving strategies and decisions taking in children and adolescents with neuromuscular disease.

- to assess the effectiveness of an online psychosocial support program and the teleassistance in this population to improve HRQoL levels through social interaction with affected equals.
Since 2004, our Neuromuscular and Neurodevelopmental Diseases research team carries out activities related to the creation, development and validation of evaluation programs, as well as psychosocial interventions, for people affected by neuromuscular diseases and neurodevelopmental disorders and their families.

The use of technologies such as Internet and Virtual Reality has allowed us to develop tools aimed at improving the quality of life of people suffering from these conditions from a psychosocial perspective.

Currently, we are working around two axes, with the collaboration of companies linked to the technological field. On the one hand, we have created on-line psychological support programs with the objective of enhancing social support among people affected by neuromuscular diseases and their families. On the other hand, we have developed different virtual reality software to evaluate and strengthen abilities related to social interaction, such as empathy or the capacity to recognise emotional facial expressions.

More information
First Step → To create a Website
Public Area

- Publications with biopsychosocial information (thesis, articles, books, databases)
- News about neuromuscular diseases
- Links: national and international associations, research centers, social resources, etc.

Private Area

- Programs
- Psychosocial support and medical advice
- Forum
Sample research

- Children and adolescents with different types of neuromuscular disease (78 subjects).
- Age: between 7 and 17 years-old.
- Location: Basque Country region.
- Most of the children belong to medium socioeconomic level families.

<table>
<thead>
<tr>
<th>online &amp; Teleassistance</th>
<th>First group</th>
<th>Second group</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>7 – 12 years</td>
<td>19</td>
<td>23</td>
<td>42</td>
</tr>
<tr>
<td>13 – 17 years</td>
<td>16</td>
<td>20</td>
<td>36</td>
</tr>
<tr>
<td>N</td>
<td>35</td>
<td>43</td>
<td>78</td>
</tr>
</tbody>
</table>
the following psycho-social variables were valued:
- Health related quality of life,
- self-esteem and
- coping strategies

semistructured interview in which qualitative and quantitative data were collected.
Between 7 and 12 years-old

- Measurement of quality of life related to the health Questionnaire in children and adolescents "KINDL" (reviewed version) (Ravens-Sieberer and Bullinger, 2000); and

- the Evaluation of the Self-esteem in Primary Education questionnaire (Ramos, Gimenez, Muñoz-Adell and Lapaz, 2006).
Between 13 and 17 years-old

- Measurement of life quality related to the health in children and adolescents questionnaire "KINDL" (reviewed Version) (Ravens-Sieberer and Bullinger, 2000);

- The Coping scale for Adolescents "ACS" (Frydenberg and Lewis, 1997); and

- the 5 form selfconcept questionnaire "AFS" (Garci y Musitu, 1999).
Psychoeducative Online Support Program

- Web sites:

  http://neuroemotion.deusto.es/

  http://neuromusculares.deusto.es/

  aventurapirata.deusto.es

These programs was designed and developed specifically for this study.

It was divided into two subprograms according to the two groups of age.
<table>
<thead>
<tr>
<th>Session</th>
<th>Theme</th>
<th>Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Nonverbal communication (smile)</td>
<td>Learn how to use the smile as an enabler in the social interactions</td>
</tr>
<tr>
<td>2</td>
<td>Nonverbal communication (look)</td>
<td>Learning to use the eye as an enabler in the social interactions</td>
</tr>
<tr>
<td>3</td>
<td>Nonverbal communication</td>
<td>Learning to recognize feelings and emotional states in others.</td>
</tr>
<tr>
<td>4</td>
<td>Perform Petitions</td>
<td>Learning to make requests adequately</td>
</tr>
<tr>
<td>5</td>
<td>Giving the Graces</td>
<td>Learning to use formulas kindness and courtesy for example: to thank.</td>
</tr>
<tr>
<td>6</td>
<td>The Greeting</td>
<td>Learning to use the greeting as an enabler in the social interactions</td>
</tr>
<tr>
<td>7</td>
<td>The Complaints</td>
<td>Learning to express anger or complaints adequately</td>
</tr>
<tr>
<td>8</td>
<td>The Conversations</td>
<td>Learn strategies to initiate, maintain and end a conversation correctly</td>
</tr>
<tr>
<td>9</td>
<td>The Presentations</td>
<td>Learning strategies in order to make themselves known to others in a proper manner.</td>
</tr>
<tr>
<td>10</td>
<td>The Relaxation</td>
<td>Learning to relax through breathing and imagination</td>
</tr>
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<td><strong>Session</strong></td>
<td><strong>Theme</strong></td>
<td><strong>Objectives</strong></td>
</tr>
<tr>
<td>------------</td>
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<td>-------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1</td>
<td>Self and Self-esteem</td>
<td>Develop and Enhance Self-esteem.</td>
</tr>
<tr>
<td>2</td>
<td>Non-Verbal Communication</td>
<td>Knowing about Social Skills and learn not Verbal fluency.</td>
</tr>
<tr>
<td>3</td>
<td>Communication skills</td>
<td>Learn strategies to initiate, maintain and end a conversation correctly.</td>
</tr>
<tr>
<td>4</td>
<td>Communication Skills 2</td>
<td>Learn strategies to initiate, maintain and end a conversation correctly.</td>
</tr>
<tr>
<td>5</td>
<td>The Assertiveness</td>
<td>Learning to use an assertive style on the interrelationship with the other.</td>
</tr>
<tr>
<td>6</td>
<td>The Request for Favours</td>
<td>Learning to make requests adequately.</td>
</tr>
<tr>
<td>7</td>
<td>Responsibility, Autonomy and Independence staff.</td>
<td>Learning to assume their own responsibilities, and to develop and enhance one's Autonomy.</td>
</tr>
<tr>
<td>8</td>
<td>Decision Making and Problem Solving Strategies.</td>
<td>Learning strategies for proper decision-making and the resolution of problems that may arise.</td>
</tr>
<tr>
<td>9</td>
<td>Inappropriate thoughts</td>
<td>Learning strategies for the management of inappropriate thoughts.</td>
</tr>
<tr>
<td>10</td>
<td>The Relaxation</td>
<td>Learning to relax through breathing and imagination.</td>
</tr>
</tbody>
</table>
The steps by the children & adolescents

- 1º Access web site.
- 2º Enter a personal code, they were provided with that code in advance, and go into the restricted area.
- 3º Access to the respective session.
- 4º Reading of theoretical instructions of the topic of the session.
- 5º Carrying out the activities that were planned on the web site.
- 6º Tasks to do at home, to spread the topics treated on the web site to their living environment..
- 7º A weekly chat group. Analysis with the therapist about the subjects treated in the sessions of that week (Only adolescents).
Results …

Quality of life (7-12 years-old)
Coping (13-17 years-old)

- To Blame Himself
  - Measurement 1: 48.57
  - Measurement 2: 69.17

- To Pay Attention in the Positive aspects
  - Measurement 1: 60.29
  - Measurement 2: 60.93

- To look for relaxing amusements
  - Measurement 1: 73
  - Measurement 2: 71
Coping (13-17 years-old)

- To ignore the Problem
- Not Coping
- To concentrate in solving the problem

<table>
<thead>
<tr>
<th>Measurement 1</th>
<th>Measurement 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>To ignore the Problem</td>
<td>33.5</td>
</tr>
<tr>
<td>Not Coping</td>
<td>43.4</td>
</tr>
<tr>
<td>To concentrate in solving the problem</td>
<td>58.2</td>
</tr>
</tbody>
</table>
- The first and the second group of age obtained scores that indicate an improvement in 50% of the cases.

- The success rate of the program in the emotional and social selfconcept sections was of 50%.
After the intervention phase is possible to see an appreciable improvement, mainly within the group of children and adolescents of 13 years old or more, talking about the perception of their quality of life.
Conclusions (II)

A reduction of some negative strategies of coping for the problems solving has been objectived, as the selfguiltness, denial of the problems and lack of coping strategies and the increase of others like concentrating in solving problems or paying attention to the positive things.
the group of small children with neuromuscular disease, with an average of age near to seven years, it seems that they did not have enough knowledge about the usefulness of the online application program. In particular, there was no a generalization of the knowledge and strategies acquired through the online program.
Conclusions (IV)

- We think that the psychological impact of the program in this group must be analyzed in a longer term.
- This program as a whole, we considered that has displayed a positive development.
Collaborators

• Dr. Gerd Ahlström (Professor of the Faculty of Health Sciences and Dean of the University of Jönköping, Sweden)
• Dr. Giovanni Meola (Prof. in Neurology at the University of Milan; Head of the Department of Neurology at the San Donato Policlinic Institute, Milan, Italy)
• Dr. Corrado Angelini (Prof. of the Neuroscience Department of the University of Padova; Head of the Department of Neurology at the San Antonio Hospital, Padova, Italy)
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Thank you

We would like to contact those research teams that might be working on this line.

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