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**Effects of Psychoeducational Intervention and Teleassistance in Children and
Adolescents with Neuromuscular Disease**

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Abstract

The aim of this study was to evaluate the effectiveness of a psychoeducational on-line program and the teleassistance for the improvement of the Health related Quality of Life in children and teenagers with neuromuscular disease.

78 subjects of the Basque Country with some type of neuromuscular disease and with ages between 7 and 17 years took part in this project. We applied and valued the following variables and instruments: first, Health related Quality of Life, Self-esteem and Coping Strategies; second, Questionnaire for the measurement of the Health related Quality of Life in children and teenagers "KINDL" and Questionnaire for the Evaluation of the Self-esteem in Primary Education "A.EP". And, in the case of teenagers: "KINDL", Scale of Coping for Teenagers "ACS" and Questionnaire Autoconcept Forms "AF5".

The two programs consisted of ten sessions constructed by different topics, with activities directed to developing and promoting the Self-esteem, the Social Abilities and the Strategies for the Resolution of Problems.

We confirm that the approach of a psychosocial online intervention and the teleassistance are valid alternatives to the traditional procedures, due to the physical limitations of the affected ones and as a way to improve their and their parents' quality of life.

Keywords: Quality of Life, Self-esteem, children and teenagers.

Introduction

Although the scientific literature related to the process of counselling online is low, the results so far have been positive and show that it can be effective in reducing the problems and symptoms that your users, highlighting their usefulness in people with disabilities or geographically isolated (Bungener, Jouvent, & Delaporte, 1998; Nätterlund, & Ahlström, 2001; Mallen & Vogel, 2005; Grootenhuis, De Boone, & Van der Kooi, 2007; Jones et al., 2014).

On the other hand, besides the considerations directly related to the therapeutic process and those that have to do with both the therapist and the patient, we must also take into account the ethical considerations that have to base all online actions. Issues such as data confidentiality, anonymity and the precautions to be taken when handling, through the network, and compromised confidential information, such as data encryption. Related to the ethical and legal aspects, we should also mention those who have to do with the legality of the online services of each community and patterns of psychological association to which the therapist belongs, and the training that is required to therapists who want to practice this emerging therapeutic modality, so that inappropriate practices are avoided (Guilcher et al., 2013).

In the scientific literature, there are very few studies that have been devoted specifically to assess the effectiveness of therapy or counselling through the therapist's role in the implementation of some kind of therapy. In this sense, many of the studies linking the information technology and communication with health focus, for example, to identify the personal characteristics of users of online support groups (Houston, Cooper & Ford, 2002), the profile of users chat (Peris et al., 2002; Glazebrook et al., 2003), the benefits of keeping chat sessions with other unknown persons (Shaw & Gant, 2002) or validation of scales of attitudes towards counselling online and face to face (Rochlen, Beretvas & Zack, 2004; Sloan et al., 2011).

They have also conducted online treatment programs health problems such as obesity (Lindemann, 1987; Longo, Moreno, & Sousa, 2005), educational programs through the web (Hubbard, Broome & Antia, 2005; Fioravanti et al., 2010) or self-administered therapies through self-help modules and exercises that can develop without the help of a professional (Harper, & Peterson, 2000; Spek et al., 2007).

There also through the network, information sheets on diseases that can share experiences among those affected, through forums or message boards where information exchange is encouraged (Howe, 1993; Bunde, Suls, Martin, & Barnett, 2007); Rotondi, Sinkule & Spring, 2005) and communication between users, reducing social isolation (Nieto, Torres, Ana, & Abad, 2003; Soutter et al., 2004). Other tools such as e-mails applied in family therapy (King, Engi & Poulos, 1998; Suler, 2004), videoconferencing (Wade Wolfe, Brown & Pestian, 2005) or the application integrated psychodynamic therapy and cognitive behavior through virtual reality have also been discussed in the scientific literature.

New technologies of information and communication represent a new application tool in the wide world of psychology, disability and neuromuscular diseases. Although this field is presented as new, as most studies have been carried out in the early years of the second millennium, there are few advantages offered: finding resources and existing aid, and the creation and maintenance of a social support network. This new field opens new hope to many people, so we must continue delving into it, but cautiously forward.

In addition, the neuromuscular diseases are genetic diseases, usually hereditary; whose fundamental symptom is atrophy and muscle weakness. Among these, a wide type is the myopathies, where there is Steiner, Becker, dystrophy of the waist, and other diseases. One of the important aspects to consider is how to deal with the disease. Problems of depression and anxiety frequently occur, these are related to uncertainty and the progressive losses. Going through the grieving process usually involves progressive social isolation related to mobility problems. Lack of communication and interaction with peers produces increased levels of stress, feelings of loneliness, defencelessness and impotence.

In this study referred to the group of children and adolescents we were asked questions such as: what are we trying to achieve with a psychoeducational intervention? What differences can there be with teleassistance? Can both types of intervention be completed? Are they necessary to improve the quality of life of these patients?

So, the main aim has been to evaluate the effectiveness of a psychoeducational on-line program and the teleassistance for the improvement of the Health related Quality of Life in children and teenagers with neuromuscular disease.

Methodology of the Study

78 subjects of the Basque Country with some type of neuromuscular disease and with ages (included) between 7 and 17 years, took part in this project (see table 1). There was realized an evaluation of the subjects, before the application of the programs, for which the following psychosocial variables were valued: Health related Quality of Life, Self-esteem and Coping Strategies.

Table 1. Sample of the Study

	Online	Teleassistance	N
7 – 12 years	19	23	42
13 – 17 years	16	20	36
N	35	43	78

These children of between 7 and 12 years were evaluated with the following questionnaires: Questionnaire for the measurement of the Health related Quality of Life in children and teenagers "KINDL" (checked Version) and the Questionnaire for the Evaluation of the Self-esteem in Primary Education "A.EP". And, the subjects between 13 and 17 years were assessed,

with another one: "KINDL" (checked Version), the Scale of Coping for Teenagers "ACS" and the questionnaire Autoconcept Forms (Trains) 5 "AF5".

The two programs consisted of ten sessions constructed by different topics, with activities directed to developing and promoting the Self-esteem, the Social Abilities and the Strategies for the Resolution of Problems.

A pre post evaluation was made, in which the following psycho-social variables were valued: Health related quality of life, self-esteem and coping strategies. The evaluation that was carried out consisted in a semi-structured interview in which qualitative and quantitative data were collected. On the one hand children between 7 and 12 years-old, were evaluated with the questionnaires: Measurement of quality of life related to the health Questionnaire in children and adolescents "KINDL" (reviewed version) (Ravens-Sieberer & Bullinger, 2000) and the Evaluation of the Self-esteem in Primary Education questionnaire (Ramos, Gimenez, Muñoz-Adell, & Lapaz, 2006).

On the other hand children between 13 and 17 years old were evaluated with the following questionnaires: Measurement of life quality related to the health in children and adolescents questionnaire "KINDL" (reviewed Version) (Ravens-Sieberer & Bullinger, 2000). The Coping scale for Adolescents "ACS" (Frydenberg & Lewis, 1997) and the 5 form self-concept questionnaire "AFS" (García, & Musitu, 1999).

The psychoeducative Online Support program applied through a web site that was designed and developed specifically for this study. The program was divided into two subprograms according to the two groups of age, one focused on children with ages between 7 and 12 years and other on children and adolescents with ages between 13 and 17 years old. Both subprograms were structured in ten sessions, 2 weekly sessions, in where they went more deeply into the different topics.

On the one hand, in the subprogram for children 7 to 12 years following topics were contemplated: nonverbal communication (smile), nonverbal communication (look) (two sessions), perform petitions, giving the graces, the greeting, the complaints, the conversations and the presentations, the relaxation; and, in the sub-program for adolescents 13 to 17 years following topics: self and self-esteem, non-verbal communication, communication skills (two sessions), the assertiveness, the request for favours, responsibility, autonomy and independence staff, decision making and problem solving strategies, inappropriate thoughts and the relaxation.

And, on the other hand, these goals were operating in each session: first, in the program of the children: learn how to use the smile and the eye as an enabler in the social interactions; to recognize feelings and emotional states in others; to make requests adequately; to use formulas of kindness and courtesy, for example, to thank; to use the greeting as an enabler in the social interactions; to express anger or complaints adequately; strategies to initiate, maintain and end a conversation correctly; strategies in order to make themselves known to others in a proper manner; and, to relax through breathing and imagination. And second, in the program of the adolescent, these were the goals: develop and Enhance Self-esteem; know about Social Skills and learn

not Verbal fluency; learn strategies to initiate, maintain and end a conversation correctly; learn strategies to initiate, maintain and end a conversation correctly; learn to use an assertive style on the interrelationship with the other; learn to make requests adequately; learn to assume their own responsibilities, and to develop and enhance one's Autonomy and Independence staff; learn strategies for proper decision-making and the resolution of problems that may arise; learn strategies for the management of inappropriate thoughts; and, learn to relax through breathing and imagination.

Results

The data collected related to the studied psychological variables (Coping, Self-esteem/Self-concept and quality of life) through different questionnaires are the following ones:

Regarding the Quality of life, although in the case of the smaller children of 7 year-old differences they were not found, in the group of children and adolescents with ages between 7 and 17 year-old, in the "pre-post", variations in the quality of life levels were detected. In particular, the improvement is more appreciable in the following indicators: emotional life and family life. In the remaining indicators, the improvement is low to medium level.

On the other hand, and regarding the coping: the children and adolescents of the clinical group between 13 and 17 years used mainly the following coping strategies. There was a significant decrease of the negative feelings of guilt. After the intervention there was a smaller incidence of self-criticisms, perception and feeling of guilty and a higher style of causal attribution of the implication in the personal problems. In the same way, we could notice a change in the positive attitude in different strategies focused on the problem. The levels of ignorance of the problem were small before the beginning of the program (38.5%) and they decreased to 30%. On the contrary, the children increased their level of implication in the problem from 58.2% to 60.7%.

And finally, regarding the self-concept and self-esteem refer: the AP-E and the AF-5 questionnaires were administrated to two differentiated groups: children with ages between 7 and 12 years old and children and adolescents with ages between 13 and 17 years old. The first group of age obtained scores that indicate an improvement in 50% of the cases. In the remaining, there is a stable situation and a slight decrease in three cases. About the group of age between 13 and 17 years old, with who an online intervention session about the self-concept was included, the results were the following:

In the first place, about the emotional self-concept, we observed that in four cases, before the beginning of the program the emotional level of self concept was medium- high or high, in one case there is a medium level and a low level in the other case. In the second evaluation, the three cases medium high or high levels stay in the same level and the fourth case couldn't take part in the program. On the contrary, two cases with previous medium low or low levels turned into medium high or high levels. The success rate of the program

in this section was of 50%. Secondly, the social self concept was evaluated, in which it is appraised an improvement in two cases and a worsening in another one. The reason of this last one obeyed to a serious worsening in the health state, which produced a home isolation that affected the capacity of the person to maintain the social networks. On the other hand, in the other two cases, maintenance of the social level of auto concept is appraised.

Discussion and Conclusions

Living with a neuromuscular disease means having to face a number of stressors, such as limitations in activities of daily living, social participation or difficulties in achieving levels of personal independence, which necessitates the use of coping strategies to overcome differences with others and especially with people of the same age (Varni et al., 1992; Calvo et al., 2015).

Several studies have found that low levels of social support in both adults and children with disabilities predict a decline in functional abilities. Children with moderate deficits physical difficulties involved in extracurricular activities are more likely to interact and establish friendships with their peers. These interactions can positively influence the functional ability of these young people by increasing opportunities for participation and motivate others to them (Bothwell et al., 2002; Evers et al., 2003; Hinton et al., 2006).

The development of the Internet has enabled the creation of new forms of communication and social participation. For teenagers, the world of technology has a special social appeal, reflected in the search for online information, access to forums, chats, social networks, games and individual activities or networks. In this regard, online support groups have experienced an increase in the recent years. Online support groups are considered as a special type of self-help and that enables people with different problems finding others with similar difficulties, share feelings and information, give advice and develop feelings of community support.

The features offered by the Internet, such as anonymity, invisibility, textuality, availability, choice of channels, access alone or in a group, make it attractive for young people (Hopps, Pepin, & Boisvert, 2003; Paul et al., 2005; Valkenburg, & Peter, 2007; Watson et al., 2012). Internet helps children and adolescents with disabilities have the opportunity to communicate with the outside world and increase their social network (Wicksell, Kilhgren, Melin, & Eeg- Olofsson, 2004; Kalkman et al., 2007; Lathouwers et al., 2009). These special features that accompany internet communication, especially those related to invisibility, facilitate the handicapping condition is not so visible, avoiding stigmatizing attitudes and behaviors. Thus, disability ceases to be a key factor in their social experience to break the differences between participants in online communication (Barak, & Dolev-Cohen, 2006; Martínez et al., 2014).

So, taking into account the data that were collected, 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. A reduction of some negative strategies of coping for the problems solving has been objective, as the self-guiltiness, 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. One of the reasons for the improvement of these variables is related with the providing of some strategies through the on-line program, different strategies focused in the improvement of their social skills, their self-control and anxiety levels (Nätterlund, Gunnarsson, & Ahlström, 2001; Edwards et al., 2014).

Although the results within the group of children and adolescents with ages between 13-17 years old seem positive, there are not significant changes in the other subgroup. There are some possible interpretations of these data. In the first place, the group of small children with a neuromuscular disease, with an average of age near to seven years, 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. This little ecological validity can be attributed to the evolutionary phase of the childhood development or the little perception of threats or losses associated to the evolution of the disease. However, we think that the psychological impact of the program in this group must be analyzed in a longer term.

At the present time, improvements related to the objectives and procedures are being introduced, specially, within the inferior group of age. This program, as a whole, we considered that has /displayed positive development.

There are few studies that describe and evaluate intervention programs online with children and adolescents with diseases in general and neuromuscular diseases in particular.

One of the questions that have tried to respond to some of these investigations is whether internet access is similar among children and adolescents who have a physical disability and those who do not. In this regard and as in children without disabilities, children use internet to a greater extent with relaxing purposes, while girls use this instrument as a means of social communication. There have been differences in children and adolescents with physical disabilities are more mediated by parental rules when internet access. This issue can be explained by the fact that parents with children with disabilities tend to be overprotective parents than mothers with healthy children (Firth et al., 1983; Lathouwers et al., 2009; Oliver, & Demiris, 2010).

On the other hand, it has been shown that computer use also helps to do homework to affected children and their siblings, and is a tool for parents seeking help games for school. Computer usage creates an occupation for children and free time for mothers. It also allows a degree of independence that helps improve self-confidence, manages to extend relationships within and outside the family, and reduce feelings of loneliness (Verdugo, & Sabeh, 2002; Calvo et al., 2015). In definitive an e-community and new contacts are undoubtedly created.

As a general conclusion, it is interesting to note that although the field of information technology and communication applied to chronic diseases is an emerging area, studies so far have been conducted to pose a positive and promising vision to respect (Piccininni, Falsini, & Pizzi, 2004; Soutter et al., 2004; Merriel et al., 2014) . In addition, the development of new longitudinal studies with larger sample sizes to consider factors such as personality characteristics of participants, the role of group moderators, the length of sessions and intervention, the size of the groups or the level suggested personal opening. In addition, research aimed at developing new theories and conceptual frameworks that serve as a guide for the implementation of technology-based interventions are needed.

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