

The eHealth well-being service for patients with SMA and other neuromuscular disorders during the COVID-19 emergency

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Abstract

The aim of the Wellbeing and Emotional Activities (WEA) project was to sustain families, to reduce the impact of COVID-19 and to create web meetings using Microsoft Teams during which children with muscular dystrophies could interact, have fun and learn. The goals of this study were to compare the perception of service users, both from the point of view of parents and children, measured with a users' satisfaction questionnaire, and to correlate if the level of satisfaction of the children could be correlated to trait self-concepts of the Piers-Harris Children's Self-Concept Scale. Eleven children with neuromuscular disorders participated in the project. The WEA program included 12 web meetings, consisting of 1 hour, 3 times a week over a 1-month period. It included game activities aimed at enhancing cognitive functions, promoting critical thinking and managing emotions. Results indicated that both children and parents perceived the same level of satisfaction.

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Correlations between children's satisfaction in life and the self-concept scale were found. This study highlights the benefits and disadvantages of the use of a WEA web-based program from the service users' perspective.

Keywords: COVID-19; Neuromuscular disorders; Emotional activities; Web meeting; Telemedicine.

1. Introduction

The Wellbeing and Emotional Activities (WEA) project originated in a historical moment in which Italy, and almost all countries in the world, are facing and experiencing the fear of Covid-19 contagion. The COVID-19 pandemic is a global emergency linked to the onset of a new virus: SARS-CoV-2 (World Health Organization, 2020). The coronavirus causes a severe acute respiratory syndrome, as demonstrated in patients treated also in Italy. This occurs with a relatively long incubation period (median 5-6 days, range 1-14 days), a viral shedding pattern documented from 1-2 days before the onset of symptoms (Coppo, Bellani, Winterton, Di Pierro, Soria, Favero *et al.*, 2020; Grasselli, Zangrillo, Zanella, Antonelli, Cabrini, Castelli *et al.*, 2020), which can be initially mild and nonspecific and that can continue for weeks after the onset of symptoms, and the presence of asymptomatic and mildly symptomatic cases capable of transmitting the infection (Grasselli, Greco, Zanella, Albano, Antonelli, Bellani *et al.*, 2020; Riccardo, Ajelli, Andrianou, Bella, Del Manso, Fabiani *et al.*, 2020). According to data published by the European Centre for Disease Prevention and Control (2020), more than 290,000 cases of SARS-CoV-2 infection and more than 35,000 deaths has been reported in Italy during 2020.

On March 2020, Italy faced the acute phase of the COVID-19 pandemic and the Italian Prime Minister declared a national lockdown (DPCM 11 March 2020) to contain, delay and mitigate the transmission and impact of this virus. Many countries, including Italy, imposed the closure of schools as well as the interruption of rehabilitation treatments that are essential for the psychophysical wellbeing of children. Thus, parents have become the only ones who can look after their children with disability, in particular children with Spinal Muscular Atrophy (SMA) and other severe congenital muscular diseases.

SMA is a genetic, progressive disorder that causes a progressive loss of spinal and bulbar a-motor neurons, due to a lack of survival motor neuron (SMN) protein caused by homozygous loss of function of the SMN1 gene (Lunn & Wang, 2008; Prior, Krainer, Hua, Swoboda, Snyder, Bridgeman *et al.*, 2009; Tisdale & Pellizzoni, 2015). Sletjes and colleagues (2020) and Polido and colleagues (2019) have described the levels of severity of the disorder, classified as type 0 in children that exhibit almost complete paralysis and have a very short survival outcome, type I in children who do not acquire the sitting function, with onset in the first semester of life, type II including children who can sit without support, with onset before 18

months of age, type III comprising children with standing and gait acquisition, with onset at a juvenile age, and type IV that begins in adulthood (Mercuri, Bertini, & Iannaccone, 2012; Wadman, Wijngaarde, Stam, Bartels, Otto, Lemmink *et al.*, 2018; Polido, de Miranda, Carvas, Mendonça, Caromano, Reed *et al.*, 2019; Sleutjes, Wijngaarde, Wadman, Otto, Asselman, Cuppen *et al.*, 2020).

Difficulties of coordination of SMA (mainly types I and II) are associated with severe weakness, which impacts hand coordination and speech acquisition. Restricted verbal and sensorimotor interaction can cause cognitive impairment. However, cognitive outcomes in SMA are contradictory in literature. For instance, the study by von Gontard and colleagues (2002) reported normal intelligence coefficients in children, and even above normal cognitive performance in adolescents with SMA types I-III (von Gontard, Zerres, Backes, Laufersweiler-Plass, Wendland, Melchers *et al.*, 2002).

In addition, as Alfano and co-workers (Alfano, Miller, Iammarino, & Lowes, 2019) pointed out, children with SMA followed video presentations, and responsiveness to change was measured through a custom-designed video game, the Ability Captured Through Interactive Video Evaluation (ACTIVE). Moreover, SMA children with normal intelligence and neurological disorders were at greater risk (24%) for adjustment problems than those without cerebral involvement (9%). Among children with physical disabilities with normal intelligence, psychiatric disorders were twice as common when the physical condition involved the disease or damage to the brain rather than a peripheral lesion (Castelli, Antonietti, Fabio, Lucchini, & Marchetti, 2013; Fabio, Magaouda, Capri, Towey, & Martino, 2018; Mohammadhasani, Fardanesh, Hatami, Mozayani, & Fabio, 2018; Polido *et al.*, 2019). Children with SMA are somewhat more likely than healthy children to show maladjustment.

The availability of data regarding emotional skills in children with SMA is limited. Overall, separation anxiety, oppositional defiant, specific and social phobia and depressive disorder are the most common psychiatric disturbances. Many of these could be a reflection of direct or indirect consequences of physical disability (van Wijk, Messelink, Heijnen, & de Groot, 2009).

Winblad and colleagues (2010) found that children with SMA showed low mood and could develop mood disturbance, given the progressive and terminal nature of neuromuscular disorders (Winblad, Jensen, Månsson, Samuelsson, & Lindberg, 2010). Indeed, internalizing behavior disorder

appears to be frequently found in children with SMA. Moreover, the loss of functional independence was reported to affect quality of life for both children and their families (Uttley, Carlton, Woods, & Brazier, 2018).

In the time of COVID-19, living without the usual support of external professionals, teachers, schools, and rehabilitation centers may become extremely difficult for both parents and children with SMA, given the reliance of many on carefully established routines and relationships. Moreover, the response to COVID-19 could affect children with SMA who depend on access to equipment and professional support that is only available in school. Consequently, parents of these children now need to meet their child's needs all day and every day, without the usual support, while potentially also managing their child's distress and anxiety as well as their own (Toseeb, Asbury, Code, Fox, & Deniz, 2020). Thus, during lockdown, the parents were the only individuals to directly provide support for children with SMA, in terms of social interactions and school homework. For this reason, we thought that children with SMA could benefit from the possibility of joining social online interactions, as during these social interactions there might be opportunities for games, surprises and learning and so on (Taber-Doughty, Shurr, Brewer, & Kubik, 2010; Zaagsma, Volkers, Swart, Schippers, & Van Hove, 2020). Thus, we designed and developed the WEA program in which both children with SMA and their parents were involved. This program consisted in online educational activities, created specifically for children with SMA, stimulating cognitive and social abilities presented through a teleconference platform, namely Microsoft Teams. In addition to the above mentioned scenario, there were two premises of the WEA project: the first was that other similar projects for children with disabilities, carried out during the Italian national lockdown, showed positive judgments on the satisfaction perceived by both children and the parents involved (Caprì, Fabio, Iannizzotto, & Nucita, 2020; Battistin, Mercuriali, Zanardo, Gregori, Lorenzoni, Nasato *et al.*, 2021; Dovigo, Caprì, Iannizzotto, Nucita, Semino, Giannatiempo *et al.*, 2021; Dovigo, Caprì, Semino, Nucita, Giannatiempo, Iannizzotto *et al.*, 2021); the second was that the tele-rehabilitation, intended as delivering rehabilitation services to the patient's home through a remote connection with the rehabilitation operator, possibly enhanced by additional multimedia technologies (Putrino, 2014), could be an effective tool for improving the adaptive skills of children with multiple disabilities (Caprì *et al.*, 2020; Caprì, Nucita, Iannizzotto, Stasolla, Romano, Semino *et al.*, 2020).

The present study had two main aims: 1) in order to support families, we created a chat-room with the Microsoft platform of the University of Messina in which parents of children with SMA or muscular dystrophies could interact with professionals and receive feedback and support; 2) to stimulate interest in children with SMA and to increase social interactions by having fun and learning. More in depth, the goals of the current study were: 1) to describe and compare the level of satisfaction of both parents and children in participating at this program; 2) to verify if the level of satisfaction of the children could be correlated to trait scale self-concepts, such as Behavioural Adjustment, Intellectual and School Status, Physical Appearance and Attributes, Freedom From Anxiety, Popularity and Happiness and Satisfaction.

2. Methods

2.1. Participants

Eleven children (10 males and 1 female), who were recruited at the NeuroMuscular Omnicentre (NeMO) of Messina, participated in the WEA project. Their age ranged between 5 and 10 years old ($M = 5.82$; $SD = 1.16$). All participants were Italian and had severe neuromuscular or musculoskeletal impairments: six children with type 2 SMA, two children with type 3 SMA, two children with Duchenne Muscular Dystrophy (DMD) and the last one with congenital muscular dystrophy type 1A (CMD1A). All participants showed sufficient upper limb motor skills and general autonomy in using a tablet or laptop. None had cognitive deficits.

All parents of children were Italian. The parents who participated in the program were predominantly female (the mother). Their age ranged between 33 to 43 years old. Their socio-economic status was medium (8 employees and 11 unemployed). Parents predominantly had a bachelor's degree.

All participants and their parents gave written informed consent.

2.2. Measures

The Piers-Harris Children's Self-Concept Scale – Second Edition (Piers-Harris 2; PHS) is a 60-item self-report questionnaire designed to assess self-concept in children aged between 5 to 18 years old. The scale yields a general measure of the respondents' overall self-concept and includes six domain scales. It can be used as a research tool, to monitor change in self-

concept over time, and as a screening tool for identifying individuals who need further testing or treatment.

The domain scales are the following: Behavioral Adjustment (BEH): a 14-item scale that measures admission or denial of problematic behavior; Intellectual and School Status (INT): a 16-item scale that measures the child's evaluation of his or her own abilities in terms of intellectual and academic tasks; Physical Appearance and Attributes (PHY): an 11-item scale that measures a child's assessment of his or her own physical appearance as well as a child's appraisal of certain personality attributes, such as the ability to express one's own ideas and leadership abilities; Freedom from Anxiety (FRE): a 14-item scale that measures anxiety and dysphoric mood; Popularity (POP): a 12-item scale that captures the child's evaluation of his or her own social functioning; Happiness and Satisfaction (HAP): a 10-item scale that measures a child's feelings of happiness and satisfaction with life.

A user satisfaction questionnaire was designed and constructed to assess the satisfaction of parents and children in which the parent section included demographic questions (age, sex, education level, marital status, employment status, children's age and sex). The questionnaire consisted of a total of 6 questions with closed responses on a 7-point Likert scale (from "Not as good" to "Very good").

The first question of both the parent and children sections evaluated the level of happiness of children in daily life. Question 2 was aimed to assess the general perception of user satisfaction; the further questions regarded the perception of activities of the WEA program (questions 3 to 4), the perception of the users' participation in homework (question 5), and the perception of the interaction with the psychologists (question 6). The questionnaire is shown in Table 1. Two examples of items (one for children and one for parents) are shown in Figure 1 and 2.

Most questions were designed based on published satisfaction surveys in telecare (Dick, Filler, & Pavan, 1999; Demiris, Speedie, & Finkelstein, 2001; Demiris, Speedie, & Hicks, 2004; Bakken, Grullon-Figueroa, Izquierdo, Lee, Morin, Palmas *et al.*, 2006). The questionnaire was administered by the experimenter.

Table 1 – *Items of satisfaction questionnaire*

Items	Items for Children	Items for Parents
Satisfaction 2	How happy were you to participate in the WEA program?	How much do you think your child was happy to participate in the WEA program?
Satisfaction 3	How much did you like the tales introduced in the activities?	How much do you think your child liked the tales introduced in the activities?
Satisfaction 4	How much did you like the emotional activities?	How much do you think your child liked the emotional activities?
Satisfaction 5	How much did you like the homework?	How much do you think your child liked the homework?
Satisfaction 6	How much did you like to play with psychologists?	How much do you think your child liked to play with psychologists?

Figure 1 – *Example of item for children*

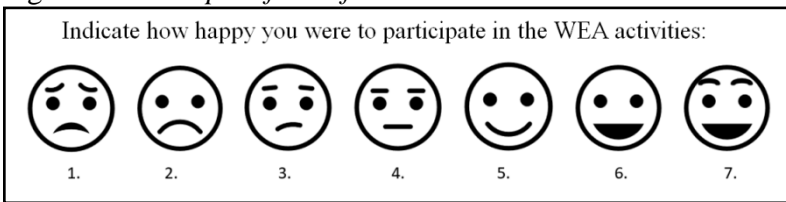
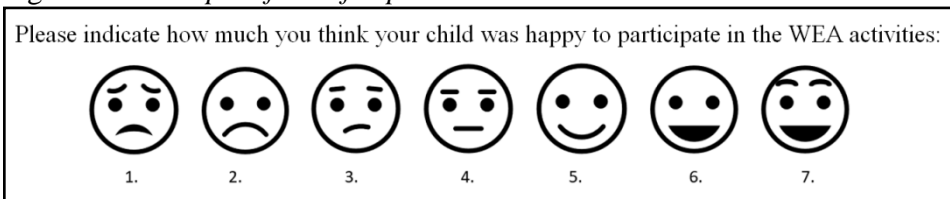


Figure 2 – *Example of item for parents*



2.3. Procedure

The program included 12 web meetings. Participants were divided into 4 groups by age (younger vs. older) and each group consisted of 2 to 4 participants. Each web meeting lasted 1 hour and was conducted 3 times a week (on Mondays-Wednesdays-Fridays) spanning a 1-month period. The program included game activities aimed at enhancing cognitive functions, promoting critical thinking and managing emotions.

Each meeting was structured on a 6-step scheme, previously validated with a group of girls and children with Rett Syndrome (Dovigo, Caprì, Iannizzotto *et al.*, 2021; Dovigo, Caprì, Semino *et al.*, 2021):

- 1st step “Opening theme song”;
- 2nd step “Greeting from the teacher and greeting from the class-members”;
- 3rd step “Presentation of the activity”;
- 4th step “Active interaction with videos related to stories, active interaction with educational materials, games of emotional and motor synchronization”;
- 5th step “Greeting from the teacher and greeting from the class-members”;
- 6th step “Homework assignment and ending theme song”.

With reference to the activities, after the second social interaction, the children were presented to the video of a cartoon story. The cartoon story changed in each meeting. It was easy to understand and remember and the descriptions of facts were presented in a logical order. The cartoon sequences were extracted from famous animation movies, such as “The ant and the grasshopper”, “The hare and the turtle”, “The crow and the fox”, “Thumbelina”, “The wolf and the seven young goats”. At the end of the cartoon sequences, a recognition test was carried out for each participant. Children were asked, in turn, to immediately recall the cartoon they had been presented to with a recognition test composed of 10 questions regarding the story. Two pictures were presented on the screen, i.e. the correct answer and the distractor answer, for each question. Participants have to reply to the ten questions in the individual virtual room. The psychologist discussed the correct replies in the general meeting room.

3. Statistical analysis

Data was analyzed using SPSS version 24.0 for Windows. The descriptive statistics of the dependent variables were tabulated and examined. The alpha level was set to .05 for all statistical tests. The Wilcoxon signed rank test was applied to compare the perceptions of service users, both from the point of view of parents and children. The Spearman's rho correlation was carried out to verify whether the level of satisfaction of the children could be correlated to the six domain scales of Piers-Harris 2.

4. Results

Table 2 shows the median and interquartile range (IQR) of the items of satisfaction questionnaire for the two groups (children and parents). With reference to the perceptions of service users, there were no statistically significant differences in the level of satisfaction between the two groups. This result indicated that both children and parents perceived the same level of satisfaction in participating in the WEA program.

Table 2 – *Median (Mdn) and interquartile range (IQR) of the items of satisfaction questionnaire for the two groups*

Items	Children group		Parents group	
	<i>Mdn</i>	<i>IQR</i>	<i>Mdn</i>	<i>IQR</i>
Satisfaction 2	7	(7-7)	6	(5-7)
Satisfaction 3	7	(6-7)	7	(6-7)
Satisfaction 4	6	(6-7)	6	(6-6)
Satisfaction 5	6	(4-7)	7	(6-7)
Satisfaction 6	6.55	(6-7)	7	(5-7)
Total scores	31	(27-35)	32	(26-34)

Table 3 shows the comparisons for each item of the satisfaction questionnaire in the children's group. There were statistically significant differences between items 2 vs 4, 2 vs 5, and 5 vs 6 ($p < .02$; $p < .01$; $p < .04$, respectively).

Table 3 – *Comparisons with the Wilcoxon signed rank test for each item of the satisfaction questionnaire in the children group*

Items	<i>p</i>
Satisfaction 2 – Satisfaction 3	.10
Satisfaction 2 – Satisfaction 4	.02
Satisfaction 2 – Satisfaction 5	.01
Satisfaction 2 – Satisfaction 6	.10
Satisfaction 3 – Satisfaction 4	.70
Satisfaction 3 – Satisfaction 5	.24
Satisfaction 3 – Satisfaction 6	1.00
Satisfaction 4 – Satisfaction 5	.07
Satisfaction 4 – Satisfaction 6	.25
Satisfaction 5 – Satisfaction 6	.04

These results indicated that the children's level of satisfaction of most activities was higher in participating in the WEA program than the emotional activities of this program; this is coherent given that the children with severe neuromuscular disorders show inadequate emotional and relational skills related to their difficulty in mobility. These results also indicated that the children's level of satisfaction was higher in participating in the WEA program in general than completing homework assigned by the psychologist of the WEA program.

Table 4 shows the median and interquartile range of the six domain scales of Piers-Harris 2.

Table 4 – *Median (Mdn) and interquartile range (IQR) of the six domain scales of Piers-Harris 2*

Subscales	<i>Mdn</i>	<i>IQR</i>
Behavioral Adjustment	3	(3-4)
Intellectual and School Status	8	(8-9)
Physical Appearance and Attributes	5	(4-5)
Freedom from Anxiety	2	(2-6)
Popularity	4	(3-4)
Happiness and Satisfaction	6	(5-6)
Total Piers-Harris 2	32	(27-34)

Table 5 shows the correlations between the items of satisfaction questionnaire and the six domain scales of Piers-Harris 2. The Spearman's rho correlation revealed a significant negative correlation between Intellectual and School Status and Happiness and Satisfaction, $r_s(11) = -.793$, $p = .01$. This result showed that the increase of children's feelings of happiness and satisfaction with life was correlated to a worse evaluation of his or her own abilities in terms of intellectual and academic tasks.

Table 6 shows the multiple comparisons between the six domain scales of Piers-Harris 2 and the normality data of Piers-Harris 2. There were statistically significant differences in all six scales. This result indicated that the children with severe neuromuscular disorders had a lower self-concept than typically developing children.

Table 5 – *Correlations with the rho coefficient between the items of satisfaction questionnaire and the six domain scales of Piers-Harris 2*

	BEH	INT	PHY	FRE	POP	HAP	Total PHS	Sat 2	Sat 3	Sat 4	Sat 5	Sat 6	Total Sat
BEH	1	-.478	.309	-.071	-.118	.060	.414	.466	.337	-.129	-.432	.066	.032
INT		1	-.034	.434	-.095	-.793**	.415	.106	-.186	-.089	.287	.321	-.012
PHY			1	.126	-.058	.000	.368	.469	-.213	-.102	-.016	-.313	.061
FRE				1	-.091	-.062	.666*	.108	-.063	-.326	-.361	.166	-.346
POP					1	-.379	.210	.055	-.390	-.215	-.044	-.262	-.167
HAP						1	-.499	-.289	.135	.065	-.268	-.339	-.119
Total PHS							1	.457	-.016	-.344	-.238	.249	-.208
Sat 2								1	.352	.168	.155	.352	.413
Sat 3									1	.687*	.099	.513	.716*
Sat 4										1	.717*	.396	.922*
Sat 5											1	.417	.683
Sat 6												1	.540
Total Sat													1

BEH = Behavioral Adjustment; INT = Intellectual and School Status; PHY = Physical Appearance and Attributes; FRE = Freedom from Anxiety; POP = Popularity; HAP = Happiness and Satisfaction; PHS = Piers-Harris 2; Sat = Satisfaction.

* The correlation is significant at the .05 level; ** The correlation is significant at the .01 level.

Table 6 – *Multiple comparisons between the six scales and the normality data of Piers-Harris 2*

Subscales	<i>t</i>	<i>p</i>
Behavioral Adjustment	7.46	.0001
Intellectual and School Status	17.57	.0001
Physical Appearance and Attributes	21.99	.001
Freedom from Anxiety	9.49	.001
Popularity	22.09	.001
Happiness and Satisfaction	17.92	.0001
Total Piers-Harris 2	15.61	.0001

5. Discussion

COVID-19 has altered the daily lives of families around the world. In Italy, one of the most significant changes for millions of families is that schools were closed for all children, including those with severe neuromuscular or musculoskeletal impairments. This sudden change, along with the necessary measures of containment of the virus, such as self-isolation and social distancing, may be particularly challenging for children with SMA or other neuromuscular disorders and their families, given that these children are often unable to move around their environment independently; therefore, they may be at risk for delays in areas of development not directly related to their motor limitations (Jones, McEwen, & Hansen, 2003).

The present brief report describes a WEA web-based program for children with progressive neuromuscular disorders, designed to contain the distress related to the COVID-19 pandemic. More specifically, the goals of this study were to compare the perceptions of service users (parents and children) and to verify whether the level of satisfaction of the children could be correlated to the six domains of the Piers-Harris 2.

With reference to the first goal, the results indicated that both children and parents perceived the same level of satisfaction in using the WEA program. This study showed that the use of the WEA web-based program was accepted by both children and their parents. This finding is line with previous studies (Alea, Fabrea, Roldan, & Farooqi, 2020; Iannizzotto, Nucita, Fabio, Caprì, & Lo Bello, 2020; Battistin *et al.*, 2021; Dovigo, Caprì, Iannizzotto *et al.*, 2021; Dovigo, Caprì, Semino *et al.*, 2021), suggesting that both children with neuromuscular impairments and their parents can benefit from the use of eHealth in support for daily functioning. de Wit and co-workers (de Wit, Dozeman, Ruwaard, Alblas, & Riper, 2015) examined the feasibility of a web-based program that could facilitate professional support in their daily functioning for service users with chronic conditions, including 10 people with mild Intellectual Disabilities (ID). Their results showed that the use of this web-based program was accepted by both professionals and service users. Moreover, the online support did not reduce service users' satisfaction with the support, empowerment, and quality of life received compared to the usual face-to-face support. In a pilot study, Taber-Doughty and colleagues (2010) compared remote telecare support with usual face-to-face support on independent performance of four adults with moderate-to-mild ID in completing household tasks. The results

indicated that service users who were supported by telecare had a higher degree of independent performance compared to usual face-to-face support. Moreover, a systematic review (Capri, Nucita *et al.*, 2020) on interventions of telerehabilitation (TR) in children with multiple disabilities (MDs) examined the effectiveness of TR on the adaptive skills and on the consumer/professional satisfaction of TR. The results suggested that TR is an effective tool in improving the adaptive skills of children with MDs. Both consumers and professionals showed high levels of satisfaction and acceptance of TR services (Capri, Nucita *et al.*, 2020).

Hence, the results of the current study are promising and may justify further research on the effectiveness of the use of eHealth in support for daily functioning. Moreover, the results observed suggest that the children's level of satisfaction of most activities was higher in participating in the WEA program than the emotional activities of this program; this is coherent given that the children with severe neuromuscular disorders show inadequate emotional and relational skills related to their difficulty in mobility.

With reference to the second goal of this study, a significant negative correlation between the children's satisfaction and happiness with life and the INT sub-scale was observed. These results could be explained by the fact that for children with severe neuromuscular or musculoskeletal impairments, socialization is often limited because of the difficulty these children have in moving on their own; consequently, their relational skills are inadequate (Qian, McGraw, Henne, Jarecki, Hobby, & Yeh, 2015). Moreover, it was reported that these children had a lower self-concept than typically developing children. This result is in line with the assumption that children with neuromuscular disorders, given this diagnosis, not only face the inevitable deterioration of physical functioning, but also become susceptible to emotional/behavioral problems (Polakoff, Morton, Koch, & Rios, 1998).

Taken together, the results of the present study are in line with the psychological profile of children with severe neuromuscular disorders, demonstrating that the children's level of satisfaction was high in participating in the general WEA program, but these children had inadequate emotional skills and self-concept, related to their poor social interactions, which affected their level of satisfaction in emotional activities of the WEA program. In addition, this study shows that these children had adequate academic skills, but these were negatively correlated with emotional activities of the WEA program, confirming again the difficulty in emotional behavior and an impaired self-concept.

This study has some limitations that should be highlighted. First, we did not use pre-post measurements. Pre- and post-tests are used to measure the knowledge gained from participating in a training or treatment program and to evaluate the effectiveness of the treatment. For this reason, it was not possible to compare the level of satisfaction of users prior and following the WEA program. Second, the sample size was small and there may be constraints to the generalization of the results. Third and last, there were no video recordings of the children's behaviors; this did not allow us to measure and evaluate implicit measures of the eHealth well-being service, such as gaze direction, facial expression and physiological reactions.

In conclusion, the present study shows that the WEA web-based program was accepted successfully by both children with severe neuromuscular disorders and their parents. The present findings were also successful in shedding light on how parents of children SMA would like to be supported during the Covid-19 pandemic. More specifically, this study suggests that e-platforms can be used both in daily living and typical clinical settings and that they have a positive impact on many levels of functioning, from cognitive to social. However, even if the results are promising, the small sample size of the study reduces their strength. Consequently, future studies could use the WEA program with a larger data set.

Moreover, from a clinical point of view, this study confirms that children with SMA have difficulty in emotional behavior and an impaired self-concept. Thus, it is important to design specific emotional training for children with SMA. This means involving children with SMA not only in motor training, but also in the treatment of emotional and psychological functions.

Hence, the present study could be seen as an initial step towards more definitive evidence to understand the benefits and disadvantages of a web-based program from the perspective of service users, contributing to the successful use of eHealth as a support for daily functioning. The idea in the near future is to develop a research design aimed to verify if this Interactive School Service could improve time of attention and motivation in Rett Syndrome (RTT) patients.

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