



Health-related quality of life and psychological wellbeing of children with Specific Learning Disorders and their mothers

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ABSTRACT

Background: Literature suggests that Specific Learning Disorders (SpLD) can cause impairment of Health-Related Quality of Life (HRQoL) and psychological well-being of children, and that this condition potentially affects parents' quality of life and well-being too.

Aims: This study aims first to explore HRQoL and psychological well-being among children with SpLD and second among mothers of children with SpLD.

Methods and procedures: Thirty children aged 8–14 years diagnosed as having SpLD and their mothers completed a battery of scales to assess children's HRQoL and psychological well-being. Mothers also completed a battery of instruments to explore their personal HRQoL and psychological well-being.

Results: Compared with the general population, children with SpLD reported significantly lower level of psychosocial health, and mothers had a higher probability of being anxious and/or depressed.

Conclusions and implications: This study supports previous research about impaired HRQoL, symptoms of generalized anxiety, school-related anxiety and depressed mood in children with SpLD. Moreover, it provides evidence that mothers of children with SpLD may experience stress in coping with their child's disability and develop socio-emotional symptoms such as anxiety. Implications concern the need to implement effective supportive services among children with SpLD and their parents.

What this paper adds?

Studies conducted so far revealed that SpLD can cause impairment of HRQoL and psychological well-being especially in self-esteem, relationship with friends and family, emotional well-being, physical well-being, and school functioning. In recent years, studies have started focus also on implications of SpLD on parents of children, finding that they experience impaired HRQoL, more parenting stress and significantly poorer psychological health. However, the interest in SpLD implications on children's and/or on their parents' well-being and quality of life is quite recent and research contributions are still scant. Moreover, due to the difficulties

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of the use of HRQoL instruments in children with SpLD, some researchers have used proxy-report measurements, but findings are contradictory and not conclusive. The present study examines HRQoL and psychological well-being among children with SpLD, by employing both self-report and proxy-report measures, and among their mothers. Findings add up to past literature by showing that, compared with the general population, children with SpLD reported significantly lower level of psychosocial health and mothers were found to have higher probability of being anxious and/or depressed.

The results of this study contribute to a better understanding of socioemotional and behavioral difficulties in children with SpLD and in their mothers and suggest the need to implement effective supportive services to assist children with SpLD as well as their parents.

1. Introduction

As indicated in the standard classification of mental disorders provided by the American Psychiatric Association (American Psychiatric Association, 2013) in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) and by the International Classification of Diseases (ICD)-11 diagnostic system (World Health Organization, 2018), Specific Learning Disorders (SpLD) is a group of neurologically based developmental disorders that become apparent in school-age, in which the normal patterns of skills acquisition are disturbed. SpLD manifest as persistent difficulties in reading (dyslexia), in spelling and writing (dysgraphia), or in mathematical and arithmetical skills (dyscalculia). SpLD are neither a mere consequence of poor instruction or socio-cultural deprivation, nor are due to intellectual disability, hearing or vision impairments or acquired conditions (e.g. brain trauma), and persist despite conventional teaching.

SpLD are estimated to affect up to 10% of the population (Butterworth & Kovas, 2013) and epidemiological studies report comparable prevalence rates of 4–9% for deficits in reading and 3–7% for deficits in mathematics (Moll, Kunze, Neuhoff, Bruder, & Schulte-Körne, 2014; for the impact of different thresholds and different criteria on the prevalence and gender ratio of developmental dyscalculia see: Devine, Soltész, Nobes, Goswami, & Szűcs, 2013).

Beyond poor school performance, children with SpLD manifest socioemotional and behavioral difficulties such as low-self-esteem, high levels of depression and anxiety, difficulties in relationships with peers and feeling of loneliness, which affect their psychological well-being (Al-Yagon, 2007, 2012). However, the interest in SpLD implications on children's and/or on their parents' well-being and quality of life (QoL) is quite recent (e.g., Karande, Bhosrekar, Kulkarni, & Thakker, 2008; Rotsika et al., 2011) and research contributions are still scant.

1.1. Quality of life of children with SpLD

Health-Related Quality of Life (HRQoL) is a multidimensional concept that is concerned with the subjective appraisal the individual's healthy functioning in the physical, mental, emotional, and social domains (Theofilou, 2013). When HRQoL of children with SpLD is compared with that of typically developing children, important differences emerge both in overall HRQoL and in specific sub-dimensions, such as self-esteem, relationship with friends, school functioning, relationship with family, emotional and physical well-being (Chan et al., 2017; Sakiz, Sart, Börkan, Korkmaz, & Babür, 2015). Specifically, children with newly diagnosed SpLD have a higher risk of being clinically anxious compared to their typically developing peers (Thakkar et al., 2016), and have been found to perceive their psychosocial, physical, and overall HRQoL to be significantly compromised (Karande & Venkataraman, 2012). Significant relations between the SpLD condition and lower emotional and scholastic well-being, self-esteem and satisfaction in children's relationships with family and friends were also found (Ginieri-Coccosis et al., 2013), and dyslexia and reading problems have been found to consistently contribute to higher depressive and anxiety symptoms in students from primary school to university (Mugnaini, Lassi, La Malfa, & Albertini, 2009). Adolescents with SpLD reported significantly higher negative affect, peer-network/peer-dyadic loneliness, and externalizing/internalizing syndromes (i.e. delinquency and aggressiveness/withdrawal, somatic complaints, anxiety and depression) than adolescents with typical development (TD) (Al-Yagon, 2012).

The use of QoL instruments in children with SpLD may be challenging, as difficulties with reading and writing may interfere with the completion of self-report measures in autonomy. In similar situations, researchers may decide to use proxies (e.g. mother, father, teacher or other family caregiver), who complete the questionnaire by rating how they think the child would rate his/her own quality of life (i.e. proxy-patient perspective), or by rating the child's quality of life in their (the proxy's) opinion (i.e. proxy-proxy perspective) (Pickard & Knight, 2005). Inconsistencies have emerged from research findings based on proxy-report and self-report measures. Whereas in some studies parents of children with SpLD tended to report lower levels of HRQoL for their children compared to children's self-reports (Chan et al., 2017; Rotsika et al., 2011, for a review: Upton, Lawford, & Eiser, 2008), other studies found an agreement of physical and emotional well-being (Sakiz et al., 2015), or significantly higher scores regarding the child's physical and emotional well-being (Rotsika et al., 2011).

1.2. Quality of life of parents of children with SpLD

Compared to educational, neurological and cognitive aspects of SpLD, family-related issues have been given less prominence in the literature (Strnadová, 2006). Findings revealed that parents of children with SpLD experience more parenting stress and reduced QoL than parents of typically developing (TD) children (Bonifacci, Storti, Tobia, & Suardi, 2016). For example, mothers of children with SpLD have reported experiencing poorer psychological health and social relationships (Karande & Kulkarni, 2009), and mild levels of anxiety have been found to emerge in mothers by the time SpLD is diagnosed, especially related to their child's poor school

performance, behavior, and future prospects in life (Karande, Kumbhare, Kulkarni, & Shah, 2009). Moreover, parents' QoL concerning social relationships has been found to affect several dimensions of children's HRQoL, i.e. (1) family, (2) friends, and (3) everyday school functioning (Ginieri-Coccosis et al., 2013).

Although the available literature agrees on that SpLD can be associated with discomfort and impairment of HRQoL and psychological well-being in both children and their families/parents, there are still under-investigated areas that deserve specific attention, including the comparison of children self-report and parent-proxy versions and a complete investigation of HRQoL and psychological well-being in parents with these children.

2. The present study

The purpose of the present study was threefold. First, we aimed at investigating HRQoL and psychological well-being of children with SpLD. Second, we investigated the agreement between child and parent proxy-reports on a child HRQoL measure. Third, we aimed at assessing mothers' HRQoL and psychological well-being.

Following the literature summarized above, we hypothesized that children with SpLD (a) have an impaired HRQoL, in both the domain of physical and psychosocial components of health, and (b) have a compromised psychosocial functioning, especially in terms of scholastic and interpersonal self-concept, anxiety and depression, as reported by both the children themselves and their proxy responders (i.e., mothers). Moreover, we hypothesized (c) that also mothers of children with SpLD would have an impaired HRQoL, (d) experience high parental distress and (e) low level of parental self-efficacy beliefs, especially concerning their efficacy as a parent in helping their children in school activities. Finally, we did not formulate a predictive hypothesis concerning the agreement between child and parent proxy-reports as previous research is inconclusive.

3. Method

3.1. Participants

Thirty children with SpLD (with single deficit or mixed forms of SpLD) and their 30 mothers participated in this study. The engagement of mothers and not fathers originates from the recent study by Bonifacci et al. (2016) which has revealed that children and mothers' psychological well-being are in some way more connected than children and fathers' psychological profiles, probably due to a typical higher involvement of mothers in their school-age children's care, in relationships with service providers, such as teachers, as well as in helping children with school homework. Inclusion criteria were as follows: children (a) had a diagnosis of SpLD provided by a Public Health Service, (b) were between 8 and 14 years old, (c) children and mothers had Italian as a first language, (d) were free from any major health problem, physical or psychiatric which could compromise their ability to comprehend the scope and the content of the study, and the battery of questionnaires, and (e) voluntarily agreed to participate in this study.

In line with the policy of the Italian Ministry of Health and the Regional Health System, the diagnosis of SpLD was provided in accordance with the ICD-10 diagnostic system, by the local health authority or by private professionals (e.g. psychologists, neuropsychiatrists) and subsequently approved by the local health authority. Information about inclusion/exclusion criteria have been obtained by the children's mothers.

Exclusion criteria included the presence of severe comorbidity (e.g. ADHD) or other conditions which may hinder the understanding of the objectives and methodology of the research.

3.2. Procedure

The study protocol was approved by the Ethical Board of the first author's university. Children and mothers were recruited in Spring 2017 in a centre for children/adolescents with diagnosis of SpLD. The centre is located in a Northern Italy region and offers assessment and intervention services for children with SpLD and their families. All the families who were in contact with the centre (about 100) were invited to participate via email. The information sheet and informed consent were provided to parents in advance and with mothers and children who fulfilled the inclusion criteria, accepted to be enrolled and signed the informed consent, a personal appointment was arranged. Child and parent questionnaires were completed at the Centre, simultaneously but separately.

Due to the characteristics of children with specific reading, spelling, or mixed learning disease, which are primarily associated with and characterized by trouble in reading and an impairment in written expression, children were asked to complete autonomously (self-completion) the battery of tests, with a psychologist nearby providing assistance to read and/or understand the items, or write the answers if requested by the child.

3.3. Measures

Children and mothers answered a set of questions to describe their socio-demographic characteristics and to specify some details on SpLD of children. Furthermore, the participants completed standardized and validated instruments to assess their HRQoL and psychological wellbeing. In the remainder of this paragraph we describe the measures included in the present study.

3.3.1. Children's measures (self-report)

3.3.1.1. *Paediatric quality of life inventory generic core scales (PedsQL™)*. PedsQL™ (Varni, Seid, & Kurtin, 2001) measures the core

dimensions of health as delineated by the World Health Organization, as well as role (school) functioning. It consists of 23 items that can be grouped into four multidimensional scales: physical functioning, emotional functioning, social functioning, and school functioning. These four scales can be grouped into summary scores: a total scale score (23 items), a Physical Health Summary Score (8 items) and a Psychosocial Health Summary Score (15 items). The instructions ask how much of a problem each item has been during the past one month (i.e. “In the past ONE month, how much of a problem has this been for you”). A 5-point response scale is used across child self-report for ages 8–18 and parent proxy-report (from 0 = never a problem, to 4 = almost always a problem). Rough item responses are rescaled into a range from 0 to 100, with 0 meaning the worst and 100 meaning the best levels of HRQoL.

3.3.1.2. The multidimensional self-concept scale (MSCS/TMA). The complete version of the MSCS (or TMA in the Italian version, [Bracken, 2003](#)) is aimed to test six self-concept dimensions (interpersonal, skills, emotional, school, family, body). For the purpose of the present study, only the school, interpersonal and family scales have been included (75 items in total). Each item requires one of four possible answers: absolutely true, true, not true, absolutely not true.

3.3.1.3. Self-administrated psychiatric scales for children and adolescents (SAFA). SAFA ([Cianchetti & Sannio Fancello, 2001](#)) is a psychometric test intended for children and adolescents aged 8–18 years, which allows a preliminary broad assessment by means of different scales that explore a wide series of symptoms and psychiatric conditions in a short period of time. It includes a total of six scales (each with subscales) that can also be used separately. For the purpose of the present study only part of the anxiety (SAFA-A1: generalized anxiety and A4: school-related anxiety) and depression (SAFA-D1: depressed mood and D3: touchy mood) sub-scales have been included (32 items in total for the children version of the questionnaire; 38 items in total for the adolescent version of the questionnaire).

3.3.2. Mothers' proxy measures (reported on behalf of their children)

3.3.2.1. Demographic information. The demographic information of children included gender, age, nationality and prevalent language spoken at home, parent-reported general school results, school year, presence of chronic diseases, diagnostic label and year of diagnosis of SpLD.

3.3.2.2. PedsQL™ parent-proxy-Report. Parent proxy-report assesses parent's perceptions of his/her child's HRQoL ([Varni & Limbers, 2009](#)). The content of the items of this parent-proxy version of the PedQL are identical to those in the child self-report version described above, while they differ for the use of developmentally appropriate language, and the use of the first (self-report) versus the third (parent-proxy version) person tense. This instrument has proved to be well accepted by parents of children with suspected learning disorder ([Mittal, Sciberras, Sewell, & Efron, 2014](#)).

3.3.2.3. Test of Anxiety and Depression (TAD), parent version. The TAD ([Newcomer, Barenbaum, & Bryant, 1995](#)) is designed to screen for symptoms of depression and anxiety in children and adolescents between the ages of 6 and 19. It includes 28 items in a true-false format, to evaluate the presence or absence of a behaviour or attribute associated with anxiety (8 items), depression (13 items), as well as children/adolescents' social difficulties/ maladjustment (7 items). Normative scores for TAD include raw scores, percentiles, and standards scores. Conversion tables for each scale and cutoff points are provided for each scale.

3.3.2.4. The strengths and difficulties questionnaire (SDQ). The SDQ ([Goodman, 1999](#); Italian version: [Tobia & Marzocchi, 2017](#)) is a brief multi-informant instrument for assessing negative and positive behavioral attributes of children and adolescents aged 3–17 years, from the point of view of their parents (SDQ-P) and for screening developmental psychopathology, as well as for studying psychosocial functioning of children with learning difficulties (e.g. [Terras, Thompson, & Minnis, 2009](#)). All versions of the SDQ ask about 25 attributes, some positive and others negative, with three response categories from zero to two (not true, somewhat true, and certainly true). These 25 items are divided in 5 scales: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, prosocial behaviour. The SDQ includes also an “impact supplement” which includes 5 items and asks whether the respondent thinks the young person has a problem, and if so, further enquire about chronicity, distress, social impairment, and burden to others.

3.3.3. Mothers' measures

3.3.3.1. Demographic information. The demographic information included mothers' age, both parents' occupation and years of education.

3.3.3.2. EQ-5D-5L. The EQ-5D-5L ([Scalone, Cortesi, Ciampichini, Cesana, & Mantovani, 2015](#)) was chosen for its capability to assess both physical and psychological components of health, furthermore it allows comparing health with the general population. It consists of two parts: a descriptive system consisting of 5 domains, namely “mobility”, “self-care”, “usual activities”, “pain/discomfort” and “anxiety/depression”, with 5 levels each, from no to extreme problems. The second part of the questionnaire consists of a visual analogue scale (EQ VAS) measuring the overall health, ranging from 0 (worst imaginable health state) to 100 (best imaginable health state). With the EQ-5D-5L the respondents are asked about their HRQoL on the current day. The responses of the EQ-5D-5L descriptive system can be converted into utility indexes by means of an algorithm that uses population-based (social) values. The utility index corresponds to the estimate of value of health with a score anchored between 0, corresponding to death, and 1, corresponding to perfect health. The Italian version of the EQ-5D-5L was tested psychometrically ([Scalone et al., 2015](#)).

3.3.3.3. Parenting stress index (PSI). The Italian version of the PSI – short form (Abidin, 1990; Guarino, Di Blasio, D'Alessio, Camisasca, & Serantoni, 2008) is a self-report screening tool with the aim of identifying potential parental behavior problems and child adjustment difficulties within the family system. The questionnaire includes 36 items with a 5-point Likert agreement response scale (from “strongly agree” to “strongly disagree”) and yields a Total Stress score and three subscales: Parental Distress, Parent–Child Dysfunctional Interaction, and Difficult Child. It also provides a Defensive Response scale.

3.3.3.4. Parental self-efficacy scales (PSE). Parenting self-efficacy can be defined as a parent’s belief about his/her ability to successfully raise children, and therefore accomplish adequately parenting function (Wittkowski, Garrett, Calam, & Weisberg, 2017). For the purpose of the present study, only two sub-scales of the Italian version of the PSE (Pastorelli & Gerbino, 2001) have been included (17 items in total). Specifically, Perceived Parental Self-efficacy in children school activities engagement scale (PSE-SA, 12 items) and the Perceived Parental Self-efficacy in children free time activities scale (PSE-FA, 5 items). The items of both sub-scales are preceded by the following statement: “As a parent, to what extent are you able to...”. Parents should respond on a 5-point Likert scale (from “not at all” to “a great extent”).

3.4. Data analysis

Raw data collected from the instruments were used to describe and measure the relevant parameters. When appropriate, the data were converted into scale scores. Sub-scales scores and total scores were analyzed using the Statistical Package for Social Sciences 23 (SPSS 23) and Stata SE 13 (Stata Corp, Texas, US) software. For the first purpose and related hypotheses, we compared the PedsQL™ scores obtained by the sample of children with SpLD with the data obtained by 275 children from general population enrolled at public regular school and comparable for age ($M_{\text{age}} \pm SD = 11.47 \pm 1.5$) and gender distribution (146 boys, 47.9%) using *t*-tests and linear regressions analyses. The data from general population were extracted from the validation study of the Italian version of EQ-5D-Y (Scalone et al., 2011).

Agreement between child self and parent proxy-report on the PedsQL™ was assessed using ICC values, Pearson product correlation coefficients and mean difference using *t*-tests. The ICC was estimated by two-way random effects model.

To test the third hypothesis, we compared the EQ-5D-5L data obtained by the sample of mothers with the reference EQ-5D-5L results by Scalone et al. (2015). In particular we compared the EQ VAS, the frequency of mothers reporting no problems vs those reporting any problems in each domain of the descriptive system, and the utility index obtained with the conversion of the descriptive system using the mapping algorithm developed by Van Hout et al. (2012) for the EQ-5D-5L.

We examined HRQoL using multiple regression analyses to provide estimations adjusted for potential socio-demographic confounders (age, gender, education). In these analyses, the dependent variable was the EQ VAS, the utility index, or a binary variable indicating having no/slight problems (coded as 0) versus having moderate/severe/extreme problems (coded as 1) in each domain of the descriptive system. When the dependent variable was the EQ VAS, we performed linear regression analyses, while the Tobit model was used for the utility index, accounting for ceiling effect (Austin, 2002; Greene, 2003), since most utilities were close or equal to 1, corresponding to an asymmetric distribution of the data. Logistic regression analyses were used to estimate the Odds Ratio (OR) as a measure of risk increase ($OR > 1$) or decrease ($OR < 1$) in perceived problems within each domain of the EQ-5D-5L descriptive system. In all these analyses, positive regression coefficients indicate a direct association, while negative regression coefficients indicated an inverse association of the dependent variable with the independent variables. The magnitude of the regression coefficients indicates the magnitude of the association. For all tests, *P*-values < 0.05 (two-tailed) were considered statistically significant and are reported together with the 95% confidence intervals where appropriate.

4. Results

4.1. Participants’ sociodemographic characteristics

Thirty children with SpLD ($M_{\text{age}} \pm SD = 12.20 \pm 1.69$; 18 boys, 60%) and their 30 mothers ($M_{\text{age}} \pm SD = 46 \pm 4.86$) participated in this study. Thirteen children had a single deficit diagnosed (either dyslexia, dysgraphia, dyscalculia, or dysorthographia), and 17 had a mixed form of SpLD with two or three impairments (e.g. dyslexia and dyscalculia.). Three children had other chronic diseases not impeding the enrollment (i.e. dermatitis and allergies, growth hormone deficiency, heart disease). Details of clinical, social and demographic characteristics of children and mothers are reported in Table 1.

4.2. Quality of life of children with SpLD

Regarding HRQoL data for SpLD children, Table 2 presents the descriptive statistics and correlations between HRQoL and psychological well-being measures.

Physical health as measured by the PedsQL™ was significantly correlated with the interpersonal dimension of the MSCS/TMA, and negatively correlated with school-related anxiety (SAFA-A4) and touchy mood (SAFA-D3), but positively with the age. The psychosocial health PedsQL™ score was positively correlated with the interpersonal and school-related and family self-concept (MSCS/TMA), and negatively correlated with generalized anxiety and touchy mood (SAFA-A4 and –D3) (see Table 2).

Raw scores of the MSCS/TMA self-concept subscales presented in Table 2 can be interpreted using the standard scores of the standardization sample and, accordingly, interpersonal and familiar self-concept of children result to be classified at an “average”

Table 1
Clinical, social and demographic characteristics.

Children with SpLD (N = 30)		Mothers (N = 30)	
Age (years) <i>M (SD)</i> [range]	12.2 (1.69) [7-14]	Age (years) <i>M (SD)</i> [range]	46 (4.86) [40-61]
Gender N (%)		Work status N (%)	
Male	18 (60)	Working	28 (93.3)
Female	12 (40)	Not working	2 (6.7)
Diagnosis N (%)		Occupation level N (%)	
Single	13 (43.3)	Executive/managerial	2 (6.7)
Mixed	17 (56.7)	Professional/teachers	8 (26.6)
Health status N (%)		Administrative Support	14 (46.7)
Without chronic diseases	27 (90)	Laborer	4 (13.3)
With chronic disease	3 (1)	Housemaker	2 (6.7)
School results N (%)		Education level N (%)	
Not sufficient	1 (3.3)	Middle school	5 (16.7)
Sufficient	8 (26.7)	High school	18 (60)
Satisfactory	12 (40)	Bachelor	1 (3.3)
Good	8 (26.7)	Master	5 (16.7)
Excellent	1 (3.3)	Post-master	1 (3.3)

Table 2
Descriptive statistics and non-parametric Spearman correlations – children with SpLD.

	<i>M</i>	<i>SD</i>	<i>α</i>	1	2	3	4	5	6	7	8	9	10	11
1 PedsQL Physical Health	76.04	11.24	.56	\	.36*	.13	.38*	.31	-.20	-.37*	-.02	-.61**	.40*	-.28
2 PedsQL Psychosocial Health	68.17	11.41	.74		\	.53**	.68**	.36*	-.46**	-.34	-.17	-.63**	.23	-.05
3 MSCS /TMA-school	64.17	6.99	.81			\	.57**	.24	-.23*	-.32	.12	-.22	.06	.02
4 MSCS /TMA -interpersonal	70.57	7.23	.83				\	.56**	-.41*	-.32	-.16	-.35	-.17	.13
5 MSCS /TMA -family	82.93	8.93	.92					\	-.30	-.12	-.30	-.06	.18	.12
6 SAFA-A1	11.50	3.92	.62						\	.56**	.41*	.47**	-.11	-.08
7 SAFA-A4	9.13	5.26	.82							\	.39*	.57**	-.19	-.05
8 SAFA-D1	2.03	2.17	.63								\	.14	.02	.03
9 SAFA-D3	5.57	3.04	.70									\	-.18	.19
10 Child Age	12.20	1.69	\										\	.24
11 Years since diagnosis	2.97	1.92	\											\

Note. MSCS /TMA = Multidimensional Self-concept Scale (raw scores); SAFA = Self-Administrated Psychiatric Scales for Children and Adolescents test; SAFA-A1 = subscale generalized anxiety; SAFA-A4 = subscale school-related anxiety; SAFA-D1 = subscale depressed mood; SAFA-D3 = subscale touchy mood. N = 30; *p < .05; **p < .01; ***p < .001 two-tailed.

position (standardized scores = 93 and 96, respectively), while school self-concept at a “slightly negative” level (standardized score = 85).

Table 3 presents the detailed results concerning anxiety and depression of children with SpLD and specifically about the dimensions of generalized anxiety, meaning tension, uneasiness and apprehensiveness, preoccupations about the future; school-related anxiety, meaning being apprehensive for school-related activities, somatized anxiety and performance anxiety related to school; depressed mood, and touchy mood. Standardized scores are calculated for each composite score, based on a normative dataset that matches participants by sex and age. Findings reveal the presence of children/adolescents with symptoms of generalized anxiety, school-related anxiety and depressed mood, especially in the age range 11-13.

To complete the analyses of the HRQoL of children, we compared the PedsQL™ scores in all QoL domains with the data obtained by 275 children from general population by using independent *t*-tests. As shown in Table 4, there were significant differences in QoL between the two groups in the total score of QoL, in the child-reported psychosocial health score and, specifically, on the domains concerning emotional and school functioning. No significant differences emerged about physical HRQoL and social domain.

According to the results of regression models on the global score obtained with the PedsQL™, including age and sex as additional predictors, we found a higher probability (*p* < .01) to have a lower level of quality of life in the SpLD children compared to the general population, while no significant effect was found due to age and sex. Specifically, the SpLD condition had a predictive effect as for psychosocial HRQoL (*p* < .01), but not on physical HRQoL (*p* = .073).

4.3. Proxy-report

We collected information about children from the mothers’ perspective. Specifically, at the SDQ five children (16.67%) with SpLD obtained a total score higher or equal to the cut-off point (90th percentile) in difficulties sub-scales, considered high or very high scores. A high or very high total difficulties score corresponds with an increased risk of a mental health disorder as, in community samples, SDQ has been proved to correctly identify four broad categories of disorder, namely conduct disorders, emotional disorders, hyperactivity disorders, and any psychiatric disorder with good specificity and moderate sensitivity (Goodman, Ford, Simmons,

Table 3
Anxiety and depression raw and standardized scores of children with SpLD.

			Males (N = 19)			Females (N = 11)			
			Raw score	T score		Raw score			T score
SAFA subscales	α	N	Mean (SD)	range	range	N	Mean (SD)	range	range
Generalized anxiety (A1)	.62								
8–10		3	12.33 (3.79)	8–15	50–66	1	6 (0.0)	6–6	47
11–13		13	11.15 (4.30)	2–17	39–71*	4	13.25 (4.35)	7–17	48–70*
14–18		3	13.00 (3.82)	12–14	68–72*	6	10.83 (4.02)	4–14	40–57
School-related anxiety (A4)	.82								
8–10		3	9.67 (1.15)	9–11	56–61	1	2 (0.0)	2–2	39
11–13		13	9.85 (5.46)	3–20	41–77*	4	14.25 (6.18)	7–22	48–75*
14–18		3	8.95 (5.04)	2–8	41–59	6	7.50 (3.39)	4–12	41–56
Depressed mood (D1)	.63								
8–10		3	1.33 (.58)	1–2	43–46	1	.00 (0.0)	0–0	39
11–13		13	1.85 (1.62)	0–4	41–55	4	4.50 (4.04)	1–10	44–72*
14–18		3	3.33 (1.15)	2–4	50–57	6	.83 (1.33)	0–3	40–47
Touchy mood (D3)	.70								
8–10		3	6.67 (1.53)	5–8	51–61	1	5.00 (0.0)	5–5	52
11–13		13	4.92 (3.25)	1–10	39–67	4	8.50 (1.29)	7–10	56–66
14–18		3	6.00 (2.81)	5–7	53–59	6	4.33 (3.88)	0–9	36–61

Note. SAFA = Self-Administrated Psychiatric Scales for Children and Adolescents. Standard scores (by sex and age groups) calculated on the standardization sample (895 children /adolescents from general population and 125 patients of Developmental Neuropsychiatric Clinic with a preliminary diagnosis). T scores: mean = 50; SD = 10. Italian norms: see Cianchetti & Sannio Fancello, 2001, 2013. * ≥ 2 SD over the mean suggest the presence of a pathology.

Table 4
Children with SpLD and children from the general population QoL scores, descriptive statistics, and independent sample *t*-test.

	Children gen. pop. (N = 275)				Children with SpLD (N = 30)				<i>t</i>	<i>p</i> .	Cohen's <i>d</i>
	Min	Max	Mean	SD	Min	Max	Mean	SD			
PedsQL™ scores											
Physical Health	37.50	100	80.50	12.43	46.88	93.75	76.04	12.24	1.87	.063	0.36
Psychosocial Health	36.67	100	75.49	12.14	46.67	88.33	68.17	11.41	2.87	.004	0.62
emotional	15	100	70.60	16.47	40	95	63.83	14.48	2.16	.032	0.69
social	25	100	83.96	14.17	35	100	81.00	17.83	1.06	.291	0.18
school	10	100	71.91	16.77	30	85	61.50	15.43	3.25	.001	0.65
Total score	36.96	100	77.23	10.99	46.88	93.75	76.04	12.24	3.14	.002	0.10

Note. Degrees of Freedom = 303.

Gatward, & Meltzer, 2000; Goodman, Renfrew, & Mullick, 2000). Particularly, in our sample, conduct problems and hyperactivity/inattention sub-scales obtained the higher percentage of children with the highest scores, i.e. ≥ 90 th percentile (5 girls, 45% and 4 boys, 21%, respectively). Both the PedsQL™ psychical and psychosocial health scores resulted to be negatively associated with the SDQ impact score ($r = -.44$ and $-.66$, respectively), the psychosocial score was also negatively correlated with the SDQ total score ($r = -.45$) and peer problems score ($r = -.50$), as well as with anxiety and depression scores (TAD-A, $r = -.42$ and TAD-D, $r = -.44$). The SDQ emotional symptoms score was also negatively associated with the diagnosis year ($r = -.36$), suggesting that emotional problems are more reported by mothers of newly diagnosed children. On the contrary, the diagnosis year was found to be correlated with the SDQ peer problems score ($r = .45$), suggesting that problems with peers appear some years after the diagnosis. Similarly, the child age was positively correlated with social difficulties/ maladjustment (TAD-SD, $r = .48$), confirming that peer relationships difficulties (especially at school) increase with time.

In order to test the level of agreement between self-report and proxy-report, we compared self-report and proxy-report scores of the PedsQL™. Table 5 presents means, correlations and *t*-test differences for both self- and proxy-reported PedsQL™ scores. Correlations between mothers' and children's reports were higher for Psychosocial Health QoL and especially for the subscale social functioning ($r = .75$ and $r = .73$ respectively). Self and proxy-report PedsQL™ scores were significantly different only concerning the Physical Health score (at $p < .01$ level, Table 5), as parents reported higher levels of children's physical health QoL than their children did. As for Psychosocial Health, parents did not underestimate the HRQoL of their children, since no significant differences were found between mean values, although mothers' scores are slightly lower than children scores.

4.4. Mothers' quality of life

Descriptive statistics and correlations between mothers' self-report measures of HRQoL and psychological well-being including

Table 5
Children and mother QoL scores, descriptive statistics, paired sample t-tests and Pearson product-moment correlations.

PedsQL scores	Mothers (proxy report)				Children (self-report)				t	r	ICC
	Min	Max	Mean	SD	Min	Max	Mean	SD			
Physical Health	59.38	100	84.89	12.24	46.88	93.75	76.04	12.24	-3.45 **	.38*	.47*
Psychosocial Health	45.00	93.33	67.28	11.48	46.67	88.33	68.17	11.41	.53	.75**	.82**
emotional functioning	35	100	62.17	16.22	40	95	63.83	14.48	-.57	.47**	.64**
social functioning	25	100	79.17	18.84	35	100	81.00	17.83	.74	.73**	.84**
school functioning	35	85	60.50	13.09	30	85	61.50	15.43	.34	.37*	.54*

Note. *p < .05, **p < .01; degrees of freedom = 29; ICC = intraclass correlation coefficients.

the EQ-5D-5L, the EQ VAS, the Parenting Stress Indexes, parental self- efficacy scales and main demographic variables are presented in Table 6.

Using the EQ-5D-5L data, problems were reported by 6.7% of them in mobility (slight), by 13.3% with usual activities (slight or moderate), by 46.7% with pain/discomfort (slight/moderate/severe), and by 66.7% with anxiety/depression (slight/moderate). Nobody reported problems with self-care. This description corresponded to a mean of 0.90 ± 0.07 in utility index, while the mean EQ VAS was 83.3±14.4.

According to the results of the regression models, and adjusting for sex, age and educational level, we found a higher probability of being anxious and/or depressed (p < .001) in mothers of children with SpLD compared with the corresponding general population. Instead, no statistical association was found with any of the other EQ-5D-5L parameters.

As shown in Table 6, the EQ-5D-5L dimensions and EQ VAS scores are correlated with several stress indexes, remarkably the anxiety and depression dimension of the EQ-5D-5L is correlated with the total stress score and with the difficult child dimension and the Parent–Child Dysfunctional Interaction dimension of the PSI; the mobility dimension is correlated with the self-efficacy for free time activities, and the year of the diagnosis has been found to be negatively correlated with the self-efficacy for free time.

A detailed analysis of parental stress scores, as assessed by the PSI, revealed that Parent-Child Dysfunctional Interaction (P-CDI) and the scale Difficult Child (DC) reported the highest percentage of mothers who obtained scores higher than the cutoff values, i.e. 85th and the 90th percentile (50% and 56.7%, respectively). Moreover, 8 mothers (26.7%) obtained a total score higher than the 90th percentile cutoff value and 15 mothers (50%) higher than the 85th percentile.

Results concerning parental self-efficacy revealed that 24 (80%) mothers had a very poor perceived ability in helping their children in school activities (PSE-SA scale), below the cut-off value (20th percentile). Similarly, 13 (43.3%) mothers obtained scores below the cut-off value (20th percentile) also on the perceived parental self-efficacy in children free time activities (PSE-FA scale).

5. Discussion

To the best of our knowledge, this is the first study analysing contemporarily HRQoL and psychological well-being among children with SpLD, using both self- and proxy-reports, and their mothers. The current findings supported our hypotheses as children with SpLD reported lower level of psychosocial health concerning emotional and school functioning, compared to children from

Table 6
Non parametric Spearman correlations and descriptive statistics – mothers of children with SpLD (self-report).

	M	SD	α	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1 EQ-5D mobility	1.07	.25	\	\	a	.27	.32	.01	-.39*	.42*	.42*	.23	.20	.36*	-.17	-.37*	-.07	.10
2 EQ-5D self-care	1	.00	\	\	a	a	a	a	a	a	a	a	a	a	a	a	a	a
3 EQ-5D usual activities	1.17	.46	\	\		.14	.15	-.09	.27	.33	.15	.03	.18	.21	-.36	-.16	-.05	-.05
4 EQ-5D pain / discomfort	1.73	.98	\	\			-.00	-.47**	.43*	.41*	.17	.07	.27	.32	.05	-.12	-.34	-.34
5 EQ-5D anxiety / depression	1.97	.81	\	\				-.10	.21	.26	.47**	.36*	.41*	-.25	.02	.09	-.09	-.09
6 VAS	83.33	14.39	\	\					-.19	-.15	-.23	-.29	-.35	-.03	.26	-.12	-.25	-.25
7 PSI - Defensive	17.10	6.04	.82	\						.96**	.62**	.46**	.74**	-.15	-.10	.12	-.17	-.17
8 PSI - Parental distress	27.37	9.59	.89	\							.61**	.52**	.76**	-.10	-.08	.07	-.24	-.24
9 PSI - Parent-Child DI	25.93	7.10	.79	\								.73**	.86**	-.19	.06	-.09	-.10	-.10
10 PSI - Difficult child	29.77	9.14	.86	\									.82**	-.21	-.06	-.10	.04	.04
11 PSI - Total score	82.07	22.55	.93	\										-.21	-.04	-.03	-.07	-.07
12 PSE-School Activities	35.87	7.63	.85	\											.225	-.324	-.058	-.058
13 PSE-Free-time Activities	18.20	3.75	.79	\												-.332	-.436*	-.436*
14 Child age	12.20	1.69	\	\														.238
15 Year diagnosis	2.97	1.92	\	\														

Note. N = 30; VAS = Visual Analogue Scale; PSI = Parental stress Index; PSE = Parental self-efficacy; EQ-5D domains: min = 1, max = 3; VAS, min = 0, max = 100; PSI dimensions: min = 12, max = 60; PSI total score: min = 36, max = 180; PSE-SA: min = 12, max = 60; PSE- FA: min = 5, max = 25; child age: min = 7 max = 14; year of diagnosis: min = 0, max = 10; *p < .05; **p < .01; ***p < .001 two-tailed.

general population. In contrast with our hypothesis and with previous literature (Karande & Venkataraman, 2012), the physical HRQoL was not perceived as compromised by children. However, according to previous research (Rotsika et al., 2011), mothers (proxy) reported higher levels of children's physical HRQoL than did their children, thus suggesting that mothers overestimate the physical HRQoL of their children. It is important to note the low value of alpha obtained for the physical HRQoL dimension could be due to sample size, as in the validation study (Varni et al., 2001) internal consistency reliability for this dimension was good ($\alpha = 0.80$).

Findings reveal the presence of children with self-reported symptoms of generalized anxiety, school-related anxiety and depressed mood, and therefore substantiate previous research concerning socioemotional and behavioral difficulties (2012, Al-Yagon, 2007; Thakkar et al., 2016). This finding was supported also by the mothers' perspective, as five mothers (16.67%) judged their children to have difficulties in behavioural and emotional domains. It is interesting to note also that, in contrast with previous research on difficulties in relationships with peers (Al-Yagon, 2007, 2012), the social sub-dimension of the psychosocial health domain appeared to be not affected in our sample of children with SpLD. However, the children's self-concept, as measured by Self-Esteem Multidimensional Test, was comparable to the average self-concept level in the standardization sample, thus indicating that children had a generally positive view of their interpersonal and familiar social competence. Conversely, children with SpLD rated their school self-esteem as lower than their counter peers in the standardization sample. This finding replicates that of Terras et al. (2009), who found no global self-esteem deficit, but a significantly lower scholastic competence than that of the general population.

As for the agreement between self-report and proxy-report and, the results revealed that mothers' and children's reports concerning the child psychosocial HRQoL are correlated and do not differ significantly. In contrast with previous evidence of a negative bias in parents' proxy QoL measurement, (for a review, see Upton et al., 2008), our results confirm some previous studies which found an agreement between children's and parent's reports (Sakiz et al., 2015) and mothers' higher scores regarding the child's physical well-being (Rotsika et al., 2011)

Finally, the results show a high prevalence (50%) of mothers who experience parental distress and who report a very poor perceived ability in helping their children in school activities (80%). The HRQoL of mothers appeared to be correlated with parental stress and self-efficacy and, compared to the corresponding general population, we found mothers of children with SpLD to have a higher probability of being anxious and/or depressed as compared with the corresponding general population. These findings are consistent with our hypothesis and previous literature (e.g. Karande et al., 2009), confirming that parents (i.e. mothers) may experience stress in coping with their child's disability and develop socio-emotional symptoms such as anxiety.

6. Strengths, limitations and future perspectives

The current findings expand our knowledge on three major aspects: (1) HRQoL and psychological well-being of children with SpLD and (2) of their mothers, as well as (3) on proxy-report measurement. It should be noted that, although prior research demonstrated socioemotional and behavioral difficulties of children with SpLD, this study provides further insights concerning the HRQoL of children with SpLD. Moreover, it contributes to better understand the relationship between self- and proxy measurements, which is still under investigation due to prior inconclusive findings. Future research is still needed to identify the factors that may affect parent-child agreement levels by using different HRQoL instruments (Cremeens, Eiser, & Blades, 2006).

The present study represents one of the few research contributions about SpLD implications on parents' well-being and HRQoL. Although further research is necessary to explore the possible reciprocal relations between parents' and children's HRQoL and psychological well-being, we may consider plausible that having a child with SpLD might have a significant impact on mothers' well-being.

Several limitations of this study call for further research. First, the present results are limited by a small sample size, and this limitation may have contributed to the observed lack of statistical significance associated with physical health between children with SpLD and the general population sample and did not allow to calculate correlation coefficients for the mothers' EQ-5D-5L self-care dimension. An enlarged sample group with a control group of TD children and their mothers would allow for a more extensive examination, especially of factors that would help explain between-group and within-group differences, as well as to investigate predictors of a low level of HRQoL and psychological well-being. Moreover, in this study we used a convenience sample composed of 30 couples mother-child (corresponding to about the 30% of the families invited to participate in the study) who decided to voluntarily participate in the study. However, self-selection bias is a risk and a potential limit of all the studies using convenience sampling and in exploratory research, and especially when the desired sample characteristic is atypical, as SpLD is.

Furthermore, while previous research has shown long-term psychological implications of dyslexia in a population of Italian university students (Ghisi, Bottesi, Re, Cerea, & Mammarella, 2016), the current study offered only data from a single point of time. Additionally, some significant correlational results concerning the year of the diagnosis suggest the need to adopt longitudinal studies to prospectively follow children from the moment of the diagnosis on.

Finally, future research should deepen the understanding of children and mother self-reports, especially by using qualitative methods (e.g. interviews) and should further investigate family and school characteristics (e.g. family cohesion, positive school-family relationships) that may influence HRQoL and psychological well-being, of both parents and children (Matteucci & Helker, 2018). As for school context, previous research (Ma & Xu, 2004) has found that prior low mathematics achievement significantly relates to later high mathematics anxiety - a negative emotional reaction concerning math tasks- which in turn may impair math achievement, and severe math difficulties associated to SpLD have been found to be strongly related to math anxiety (Rubinsten & Tannock, 2010). In this vein, the role of teachers is worthy of further investigation, as negative experiences with math teachers may compound this downward spiral, and math anxiety of female elementary school teachers carries negative consequences for the math

achievement of their female students (Beilock, Gunderson, Ramirez, & Levine, 2010).

7. Conclusion

The present study has expanded the research concerning SpLD and especially on parents of children with SpLD, which is still scarce. SpLD are commonly considered and investigated as an individual variable and interventions or supportive services are mainly focused on the child (Matteucci & Farrell, 2018), however SpLD should be considered as a health condition with multifaceted relations with the social and developmental context. In general, the current findings suggest the need to develop and implement effective interventions among children with SpLD, which need to include also their parents and especially mothers. As behavioral problems and social competence of children with SpLD are related to their parents' stress (Dyson, 2003), we can speculate that improving parents' own adjustment and establish a supportive home environment may improve HRQoL and psychological well-being of children.

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