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Article

Coping Strategies and Sense of Care Among Parents with Offspring Affected by Sturge-Weber Syndrome

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Abstract

Background/Objectives: The diagnosis of a rare disease, such as Sturge-Weber syndrome, in a newborn has a profound emotional impact on parents and presents a significant challenge, as they must face an unexpected and unfamiliar reality. The aim of this study was to analyze the meaning of caregiving among parents of children with Sturge-Weber Syndrome, identifying the different coping styles they adopt. **Methods**: A cross-sectional descriptive study was conducted with 28 parents of children with Sturge-Weber Syndrome in Spain. Data were collected using the Brief COPE inventory and the Finding Meaning Through Caregiving Scale (FMTCS). **Results**: Responses from 28 participants were analyzed, revealing that parents experienced a sense of fulfillment in providing meaning to the care of their children, coping with the diagnosis, and assessing their child's development. A higher sense of care was observed in families where both parents cohabited. Additionally, as the affected descendant grew older, the perceived sense of care increased. **Conclusions**: The most frequently used coping strategies among parents were active coping and acceptance of the disease, regardless of sociodemographic characteristics. As parents aged, they began to adopt additional strategies such as emotional venting, positive reframing, or humor.

Keywords: rare diseases; Sturge-Weber syndrome; caregivers; mothers; parents; meaning in caregiving; coping skills

1. Introduction

Rare diseases are defined as "those that, posing a risk of death or chronic disability, have a prevalence of fewer than 5 cases per 10,000 inhabitants," according to the European Union's expert committee [1]. These figures indicate that over 300 million people worldwide are affected by at least one of the 6,000 known rare diseases, with pediatric onset in most cases and a genetic etiology in approximately 70% of instances [2].

Sturge-Weber syndrome (SWS) is a congenital, sporadic neurovascular disorder most often caused by a mutation in the GNAQ gene on chromosome 9q21 [3]. In Europe, the prevalence is estimated at 1 in 20,000–50,000 live births [4]. The main vascular malformations associated with this syndrome include a facial capillary malformation (port-wine stain on the upper part of the face), glaucoma, and a leptomeningeal malformation in the brain, which is the primary cause of seizures in the first months of life [5].

Due to the severity and extent of these malformations, each individual with SWS will present a different degree of impairment. Possible complications include hemiparesis or acquired vision loss

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[6–9], cerebral atrophy and calcifications [10], stroke events [11], intellectual disabilities [12], odontological manifestations [13] and autism spectrum disorders [14,15].

SWS is a multisystemic disorder requiring affected individuals to receive care from various specialists. A multidisciplinary team is essential, comprising experts specializing in endocrinology, psychiatry, dermatology, and ophthalmology, as well as providing rehabilitation services for mobility, motor skills, and speech therapy. In addition, many patients with Sturge-Weber syndrome experience drug-resistant epilepsy, which may require surgical evaluation and intervention. Therefore, neurosurgeons and neurologists play a crucial role within the multidisciplinary team, working alongside other specialists to optimize seizure control and neurological outcomes [16–21].

This disease profoundly impacts both patients and their families at biological, psychological or emotional levels. The diversity and variability of symptoms and disease progression lead to a highly individualized clinical presentation, with each case manifesting differently [22].

The diagnosis of a rare disease has a major emotional impact on the entire family, particularly on the mother and father, as it unexpectedly disrupts the family biography and demands a profound restructuring of lifestyle, expectations, and parental roles, thereby transforming the emotional, social, and functional dynamics of family life. The required adaptations may include implementing medical or surgical treatments, dietary changes, work adjustments, and a reorganization of daily routines [23,24].

Having a child with a rare disease triggers a unique coping process, distinct from coping with one's own illness, as it evokes intense feelings of vulnerability and loss of control—amplified by the scarcity of available information, limited access to specialists, and the lack of specific treatments—resulting in a pervasive sense of helplessness and uncertainty. The diagnostic delay, common in rare diseases, often intensifies the emotional burden experienced by parents, who must navigate long periods of uncertainty before obtaining a definitive answer [25].

In this context, parents may experience overwhelming emotions such as guilt, fear of their child's death, and stress arising from the unpredictability of the clinical course and the perceived loss of the "ideal child" imagined before the diagnosis. Feelings of insecurity, sadness, frustration, anger, and hopelessness are also common, often coexisting with denial and other defense mechanisms that aim to mitigate the immediate emotional shock [25].

As the process evolves, more adaptive coping strategies tend to emerge, oriented toward seeking information and social support, although these are frequently accompanied by physical and mental exhaustion. Coping strategies become essential and are closely related to the care provided to the child as well as to the overall quality of life of the family unit [26,27].

The aim of this study was to analyze the sense of care among parents of descendants affected by Sturge-Weber syndrome, identifying the coping styles they adopt.

2. Materials and Methods

2.1. Design

This is a cross-sectional descriptive study conducted with parents of descendants affected by Sturge-Weber syndrome in Spain.

2.2. Participants and Settings

The study aimed to reach the entire population of parents with descendants affected by Sturge-Weber syndrome by recruiting participants through the Asociación Española de Sturge Weber (AESSW). This approach was chosen because most affected individuals in Spain are concentrated within patient associations, where parents seek others experiencing similar situations to exchange relevant disease-related information and provide mutual emotional support [28].

2.3. Data Collection

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Data were collected using an online, fully voluntary, and anonymous questionnaire, which was disseminated through AESSW. Once initial contact was established via email with the principal investigator, the association distributed the questionnaire to its members through electronic communication channels.

The sociodemographic variables included in the questionnaire were: parental role (mother or father), age, family type based on whether both parents cohabited (as described by Irueste et al.: nuclear, single-parent, separated parents, or blended family), age of the affected child, number of children, birth order of the affected child, education level (compulsory education, secondary education, vocational training, or university studies), and employment status (subsidy for child care [CUME], unemployment, part-time employment, or full-time employment). The latter two categories were created based on the Spanish Labour Force Survey from the National Institute of Statistics [29].

Additionally, two validated instruments were used to assess coping strategies and the sense of meaning in caregiving: the Brief COPE scale [30,31] and the Finding Meaning Through Caregiving Scale (FMTCS) [32,33] both adapted for the Spanish population.

2.4. Brief COPE

The Brief COPE questionnaire was used to measure the coping strategies parents employed in response to the diagnosis and progression of their child's disease. It consists of 28 items subdivided into 14 different coping styles, each rated on a 4-point ordinal Likert scale ranging from 0 ("I never do this") to 3 ("I always do this"), with intermediate scores. Each coping style has a minimum score of 0 and a maximum of 6, as defined by Carver [30] and translated into Spanish by Morán Astorga et al. [31]. The 14 resulting subscales are: active coping, planning, use of instrumental support, use of emotional support, self-distraction, venting, behavioral disengagement, positive reframing, denial, acceptance, religion, substance abuse, humor and self-blame.

Finding Meaning Through Caregiving Scale (FMTCS)

This scale aims to identify both positive and negative feelings and how each parent copes with caregiving, seeking meaning in their own existence through caregiving. The Spanish adaptation by Fernández Capo and Gual García [33] was used, based on the original version by Farran et al. [32].

The FMTCS is a self-administered Likert-type scale consisting of 43 items, each rated from 1 to 5 according to agreement or disagreement. The scale is structured into four subscales: provisional meaning, loss/powerlessness, ultimate meaning and total meaning.

2.5. Data Analysis

All statistical analyses were conducted using IBM SPSS Statistics version 22. Prior to inferential analyses, data were screened for missing values, outliers, and distributional assumptions. Normality of each variable was assessed using Shapiro–Wilk tests and inspection of Q–Q plots. Because several variables did not meet normality assumptions, non-parametric tests were applied. No data transformations were necessary.

Outliers were examined using standardized residuals ($|z| > 3.29$) and Cook's D ($> 4/n$); analyses were replicated including and excluding these cases, yielding consistent results. Missing data were below 5% and were handled by pairwise deletion.

Descriptive statistics were used to summarize the variables: measures of central tendency (mean or median) and dispersion (standard deviation [SD] or interquartile range [IQR]) for quantitative variables, and absolute frequencies and percentages for qualitative variables.

For the bivariate analyses, Mann–Whitney U and Kruskal–Wallis H tests were used to explore the influence of sociodemographic characteristics on coping styles and sense of caregiving. Associations between sense of caregiving and coping styles were examined using Spearman's rank correlation coefficient (ϱ) with 95% confidence intervals.

The significance threshold was set at $p = 0.05$ (two-tailed). Given the exploratory nature and small sample size typical of rare-disease research, no correction for multiple comparisons was applied; exact p-values are reported to allow interpretation of potential type I error inflation.

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Because of the limited sample (n = 28), multivariable regression analyses were not conducted. Instead, bivariate non-parametric tests were used to explore associations between coping strategies and sense of care.

3. Results

The sample comprised 28 parents (19 mothers and 9 fathers) of children diagnosed with Sturge–Weber Syndrome. Participants had a mean age of 43.3 years (SD = 5.2). The mean age of the offspring diagnosed with Sturge–Weber Syndrome was 8.0 years (SD = 5.2; range = 1–21).

A total of 82.1% of participants identified as belonging to a nuclear family, defined as one in which both parents cohabit in the family home. Regarding employment status, the majority of participants (n = 17) were employed full-time. Nearly half of the participants had a university-level education, with similar proportions distributed across other levels of education. The maximum number of children per family was three (reported by nine participants, 32.1%). The birth order of the child diagnosed with Sturge–Weber Syndrome within their siblings was second in 50% of cases (Table 1).

Table 1. Description of the sample studied (global and disaggregated by parental role).

		Global (n=28; 100%)		**Mothers (n=19; 67,9%)**		**Parents (n=9; 32,1%)**	
Variables		**Mean (SD)**	**Min-Max**	**Mean (SD)**	**Min-Max**	**Mean (SD)**	**Min-Max**
Age (n=28)		43.3(5,2)	34-54	41.84 (4,4)	34-49	46.4(5,6)	38-54
Age Offspring with SWS		8 (5,2)	1-21	7,3 (4,6)	1-18	9.44 (6,2)	3-21
Variable	**Categories**	**n**	**%**	**n**	**%**	**n**	**%**
Family type	Nuclear	23	82.1%	14	73.7%	9	100%
	Single-parent	3	10.7%	3	15.8%		
	Separated parents	2	7.1%	2	10.5%		
Employment status	CUME Subsidy	3	10.7%	3	15.8%		%
	Unemployment	5	17.9%	4	21.1%	1	11.1%
	Part time employment	3	10.7%	3	15.8%		%
	Full time employment	17	60.7%	9	47.4%	8	88.9%
Educational level	Primary	4	14.3%	3	15.8%	1	11.1%
	Secondary	5	17.9%	4	21.1%	1	11.1%
	Vocational training	6	21.4%	5	26.3%	1	11.1%

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	University	13	46.4%	7	36.8%	6	66.7%
Number of children	1 offspring	4	14.3%	3	15.8%	1	11.1%
	2 offsprings	15	53.6%	8	42.1%	7	77.8%
	3 offsprings	9	32.1%	8	42.1%	1	11.1%
Birthorder of offspring with SWS	First child	7	25%	4	21.1%	3	33.3%
	Second child	14	50%	9	47.4%	5	55.6%
	Third child	7	25%	6	31.6%	1	11.1%

SD (standard deviation).

3.1. Brief COPE

The most frequently used coping strategies among parents of children with Sturge-Weber syndrome, based on their mean scores, were acceptance, with a mean of 5.14 (SD: 0.848), and active coping, with a mean of 5.07 (SD: 1.120). These were followed by positive reframing, which also had a mean score above 4 points.

In contrast, denial, behavioral disengagement, and substance use were rarely employed by participants, with mean scores below 1 point (Table 2).

Table 2. Description of Brief Cope.

Coping styles	Mean	SD	Median	Minimum	Maximum	IQR
Active Coping	5.07	1.120	5.50	2	6	2
Planning	3.79	1.813	4.00	0	6	3
Use of instrumental support	3.75	1.713	4.00	1	6	3
Use of emotional support	3.89	1.474	4.00	2	6	2
Self-distraction	2.18	1.657	2.00	0	6	2
Venting	2.46	1.774	2.00	0	6	3
Behavioral disengagement	0.61	1.166	0.00	0	4	1
Positive reframing	4.07	1.676	4.00	0	6	2
Denial	0.50	1.036	0.00	0	4	1
Acceptance	5.14	0.848	5.00	3	6	1
Religion	1.57	2.168	0.00	0	6	4
Substance abuse	0.04	0.189	0.00	0	1	0
Humor	2.18	1.982	2.00	0	6	4
Self-blame	1.61	1.449	1.00	0	5	2

SD (standard deviation), Interquartile Range (IQR).

Older parents tended to adopt alternative coping strategies, such as humor (Rs = 0.449; p = 0.016) and venting (Rs = 0.518; p = 0.005). This suggests that as parents age, they become more capable of making jokes or laughing about the stressor, as well as increasing awareness of their own emotional distress and expressing their emotions to release tension. Additionally, when considering the age of the descendant with Sturge-Weber syndrome, statistically significant differences were observed, indicating that parents tend to adopt alternative coping strategies such as acceptance (Rs = 0.397; p = 0.036), instrumental support (Rs = 0.512; p = 0.005), emotional support (Rs = 0.441; p = 0.019), positive

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reframing (Rs = 0.397; p = 0.036), humor (Rs = 0.501; p = 0.007), and venting (Rs = 0.542; p = 0.003) (Table 3).

Table 3. Age and Age offspring with SWS correlation with Brief Cope.

		Age	Age Offspring with SWS
Variable	**Categories**		
Active coping	Spearman correlation	0.098	0.335
	p Value	0.618	0.081
Planning	Spearman correlation	0.309	0.342
	p Value	0.109	0.075
Use of instrumental support	Spearman correlation	0.351	0.512
	p Value	0.067	0.005
Use of emotional support	Spearman correlation	0.160	0.441
	p Value	0.417	0.019
Self-distraction	Spearman correlation	0.258	0.260
	p Value	0.184	0.182
Venting	Spearman correlation	0.518	0.542
	p Value	0.005	0.003
Behavioral disengagement	Spearman correlation	0.177	-0.161
	p Value	0.367	0.414
Positive reframing	Spearman correlation	0.324	0.397
	p Value	0.093	0.036
Denial	Spearman correlation	-0.084	-0.062
	p Value	0.670	0.752
Acceptance	Spearman correlation	0.024	0.397
	p Value	0.903	0.036
Religion	Spearman correlation	0.096	0.232
	p Value	0.627	0.236
Substance abuse	Spearman correlation	0.095	0.132
	p Value	0.629	0.504
Humor	Spearman correlation	0.449	0.501
	p Value	0.016	0.007
Self-blame	Spearman correlation	0.334	0.277
	p Value	0.082	0.154

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3.1.1. Associations

The bivariate analysis of the scale (Table 4) revealed differences in coping style means between fathers and mothers, although these differences were not statistically significant. However, regarding family type, statistically significant differences were observed in self-distraction (5.0 vs. 3.0 and 1.8; p = 0.035) and substance use (0.5 vs. 0 and 0; p = 0.002), with higher means among separated parents compared to other family types. Additionally, parents who remain together exhibit lower levels of denial regarding the disease compared to those facing it individually (0.2 vs. 2.0 and 1.5; p = 0.055).

Table 4. Bivariate analysis Brief COPE.

			Active coping		Planning		Use of instrumental support		Use of emotional support		Self-distraction	
Variable	**Categories**	**n**	**Mean (SD)**	**P Value**	**Mean (SD)**	**P Value**	**Mean (SD)**	**P Value**	**Mean (SD)**	**P Value**	**Mean (SD)**	**P Value**
Parental role	Mother	19	5.3 (1.0)	0.263	3.8 (1.9)	0.735	3.7 (1.9)	0.962	3.9 (1.4)	0.962	2.5 (1.7)	0.188
	Father	9	4.7 (1.3)		3.7 (1.6)		3.8 (1.6)		3.9 (1.7)		1.6 (1.3)	
Family type	Nuclear	23	4.9 (1.2)	0.229	3.7 (1.9)	0.235	3.7 (1.7)	0.819	3.9 (1.5)	0.781	1.8 (1.5)	0.035
	Single-parent	3	5.7 (0.6)		3.0 (1.0)		4.3 (1.2)		3.7 (1.2)		3.0 (1.0)	
	Separated parents	2	6.0 (0.0)		5.5 (0.7)		4.0 (2.8)		4.5 (0.7)		5.0 (0.0)	
Employment status	CUME Subsidy	3	5.0 (1.0)	0.091	3.7 (2.1)	0.505	4.0 (1.7)	0.298	3.3 (1.5)	0.648	1.7 (0.6)	0.226
	Unemployment	5	4.8 (1.3)		2.4 (2.2)		2.4 (1.7)		3.6 (1.1)		1.2 (1.3)	
	Part time employement	3	6.0 (0.0)		4.0 (1.7)		4.0 (2.6)		3.3 (1.5)		3.7 (1.5)	

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	Full time employment	17	5.0 (1.1)		4.2 (1.6)		4.1 (1.5)		4.2 (1.6)		2.3 (1.8)	
Educational level	Primary	4	6.0 (0.0)	0.184	3.8 (2.9)	0.424	4.8 (2.5)	0.030	5.3 (1.0)	0.059	2.8 (3.2)	0.339
	Secondary	5	4.8 (0.8)		2.6 (2.2)		1.8 (0.8)		3.0 (1.7)		1.0 (1.0)	
	Vocational training	6	5.2 (1.3)		4.3 (1.0)		4.5 (1.4)		4.5 (1.0)		2.2 (1.3)	
	University	13	4.9 (1.2)		4.0 (1.6)		3.9 (1.3)		3.5 (1.4)		2.5 (1.3)	
Number of children	1 offspring	4	6.0 (0.0)	0.070	4.5 (1.3)	0.533	4.0 (2.2)	0.651	4.0 (1.4)	0.361	3.0 (1.4)	0.431
	2 offsprings	15	5.1 (1.2)		3.4 (2.0)		3.9 (1.8)		4.2 (1.5)		2.0 (2.0)	
	3 offsprings	9	4.7 (1.0)		4.1 (1.0)		3.3 (1.4)		3.3 (1.4)		2.1 (0.9)	
Birthorder of offspring with SWS	First child	7	5.3 (0.9)	0.328	4.4 (1.3)	0.580	4.1 (1.6)	0.502	4.3 (1.4)	0.154	2.7 (1.4)	0.344
	Second child	14	5.1 (1.4)		3.4 (2.1)		3.9 (2.0)		4.1 (1.5)		1.9 (2.0)	
	Third child	7	4.7 (0.8)		3.9 (1.7)		3.1 (1.0)		3.0 (1.4)		2.3 (1.0)	

Table 4: Bivariate analysis Brief Cope. Continuation

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			Venting		Behavioral disengagement		Positive reframing		Denial		Acceptance	
Variable	Categories	n	Mean (SD)	p Value	Mean (SD)	p Value	Mean (SD)	p Value	Mean (SD)	P Value	Mean (SD)	p Value
Parental role	Mother	19	2.6 (1.8)	0.629	0.5 (1.1)	0.562	4.0 (1.7)	0.562	0.7 (1.2)	0.357	5.3 (1.1)	0.263
	Father	9	2.2 (1.8)		0.9 (1.8)		4.2 (1.7)		0.1 (0.3)		4.8 (0.7)	
Family type	Nuclear	23	2.3 (1.6)	0.085	0.5 (1.0)	0.132	4.2 (1.5)	0.635	0.2 (0.5)	0.055	5.1 (0.9)	0.791
	Single-parent	3	2.0 (1.7)		2.0 (2.0)		3.7 (1.2)		2.0 (2.0)		5.0 (1.0)	
	Separated parents	2	5.5 (0.7)		0.0 (0.0)		3.0 (4.2)		1.5 (2.1)		5.5 (0.7)	
Employment status	CUME Subsidy	3	1.7 (0.6)	0.414	0.0 (0.0)	0.667	3.7 (0.6)	0.005	0.3 (0.6)	0.251	5.0 (1.0)	0.900
	Unemployment	5	1.6 (2.2)		1.0 (1.7)		2.6 (2.1)		0.8 (1.8)		5.4 (0.6)	
	Part time employment	3	3.0 (2.6)		0.7 (1.2)		2.0 (3.5)		1.7 (1.5)		5.0 (1.0)	
	Full time employment	17	2.8 (1.6)		0.6 (1.1)		4.9 (1.0)		0.2 (0.6)		5.1 (0.9)	
Educational level	Primary	4	4.0 (2.7)	0.125	0.8 (1.5)	0.895	3.5 (2.6)	0.612	0.8 (1.5)	0.218	5.3 (0.5)	0.941
	Secondary	5	1.2 (0.8)		0.2 (0.4)		3.6 (1.9)		0.0 (0.0)		5.2 (0.4)	
	Vocational training	6	3.2 (1.5)		1.0 (1.7)		4.8 (1.2)		1.3 (1.6)		5.3 (0.8)	
	University	13	2.2 (1.5)		0.5 (1.1)		4.1 (1.5)		0.2 (0.4)		5.0 (1.1)	
Number of	1 offspring	4	3.5 (1.9)	0.342	1.0 (2.0)	0.959	3.3 (2.4)	0.658	1.8 (2.1)	0.260	5.8 (0.5)	0.178

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childr en	2 offsprings	15	2.5 (2.0)		0.5 (1.0)		4.2 (1.8)		0.3 (0.7)		5.1 (0.8)	
	3 offsprings	9	1.9 (1.1)		0.6 (1.1)		4.2 (1.1)		0.2 (0.4)		4.9 (0.9)	
Birtho rder of offspri ng with SWS	First child	7	3.0 (1.6)		0.9 (1.6)		4.0 (2.0)		1.4 (1.6)		5.6 (0.5)	
	Second child	14	2.6 (2.1)	0.405	0.4 (0.9)	0.846	4.0 (1.8)	0.991	0.1 (0.5)	0.036	5.1 (0.9)	0.1 56
	Third child	7	1.7 (0.8)		0.7 (1.3)		4.3 (1.3)		0.3 (0.5)		4.7 (1.0)	

Table 4: Bivariate analysis Brief Cope. Continuation

			Religion		Substance abuse		Humor		Self-blame	
Variable	**Categories**	**n**	**Mean (SD)**	**p Value**	**Mean (SD)**	**p Value**	**Mean (SD)**	**p Value**	**Mean (SD)**	**p Value**
Parental role	Mother	19	1.6 (2.2)	1.000	0.1 (0.2)	0.847	2.0 (2)	0.357	1.8 (1.6)	0.285
	Father	9	1.6 (2.2)		0.0 (0.0)		2.7 (2)		1.1 (1.1)	
Family type	Nuclear	23	1.6 (2.1)	0.100	0.0 (0.0)	0.002	2.3 (2.0)	0.707	1.5 (1.4)	0.275
	Single-parent	3	0.0 (0.0)		0.0 (0.0)		1.3 (2.3)		1.3 (0.6)	
	Separated parents	2	4.0 (2.8)		0.5 (0.7)		2.0 (2.8)		3.5 (2.1)	
Employment status	CUME Subsidy	3	1.7 (2.1)	0.251	0.0 (0.0)	0.040	1.7 (1.5)	0.231	1.3 (1.5)	0.142
	Unemployme nt	5	0.0 (0.0)		0.0 (0.0)		1.4 (1.9)		0.6 (0.9)	
	Part time employment	3	2.0 (3.4)		0.3 (0.6)		0.7 (1.2)		2.0 (2.6)	
	Full time employment	17	1.9 (2.2)		0.0 (0.0)		2.8 (2.0)		1.9 (1.3)	

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Educational level	Primary	4	2.5 (3.0)	0.626	0.3 (0.5)	0.112	3.0 (2.2)	0.555	2.3 (2.6)	0.537
	Secondary	5	1.0 (1.7)		0.0 (0.0)		1.2 (1.8)		0.8 (0.4)	
	Vocational training	6	1.0 (2.4)		0.0 (0.0)		2.2 (2.6)		1.7 (1.9)	
	University	13	1.8 (2.0)		0.0 (0.0)		2.3 (1.8)		1.7 (1.0)	
Number of children	1 offspring	4	1.5 (3.0)	0.885	0.3 (0.5)	0.050	2.3 (1.7)	0.418	1.8 (2.4)	0.958
	2 offsprings	15	1.7 (2.3)		0.0 (0.0)		2.6 (2.2)		1.6 (1.4)	
	3 offsprings	9	1.3 (1.8)		0.0 (0.0)		1.4 (1.7)		1.4 (1.1)	
Birthorder of offspring with SWS	First child	7	3.1 (3.0)	0.204	0.1 (0.4)	0.223	2.3 (1.9)	0.541	2.3 (2.1)	0.425
	Second child	14	0.8 (1.3)		0.0 (0.0)		2.5 (2.1)		1.2 (1.1)	
	Third child	5	1.6 (2.2)		0.0 (0.0)		1.4 (1.8)		1.7 (1.1)	

SD (standard deviation).

Parental employment status was also found to influence coping strategies, particularly positive reframing (p = 0.005). Parents employed full-time (4.9; SD: 1.0) were more likely to engage in this coping mechanism, focusing on growth and identifying positive aspects in their child's condition. Additionally, participants working part-time exhibited higher substance use (0.3 vs. 0; p = 0.040).

Regarding educational level, statistically significant differences were found in the use of instrumental support (p = 0.030), with higher scores among parents with compulsory education (4.8; SD: 2.5) and vocational training (4.5; SD: 1.4). These parents were more likely to seek advice, assistance, and guidance from their close social network.

Parents whose child with Sturge-Weber syndrome was their firstborn displayed higher levels of denial compared to those who had the affected child in the second or third position within their offspring (1.4 vs. 0.1 and 0.3; p = 0.036). Similarly, denial was also more prevalent among parents with only one child (1.8 vs. 0.3 and 0.2).

3.2. Finding Meaning Through Caregiving Scale (FMTCS)

Regarding the Finding Meaning Through Caregiving Scale (FMTCS) (Table 5), the total meaning score yielded a mean of 164.50 (SD: 19.73), with values ranging from 112 to 204.

Table 5. Description of FMTCS.

Subscales	Mean	SD	Median	Minimum	Maximum	IQR

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Provisional meaning	71.85	7.76	74.50	51	85	9
Loss/Powerlessness	73.60	14.75	74.00	43	95	22.50
Ultimate meaning	19.03	7.32	18.50	10	35	12.75
Total meaning	164.50	19.73	163.00	112	204	28

SD (standard deviation), Interquartile Range (IQR).

In the Provisional Meaning subscale, which assesses how participants find meaning in their daily lives through caregiving, including decision-making and recognizing positive aspects of their role, the mean score was 71.85 (SD: 7.76).

The Loss/Powerlessness subscale, which measures the exhaustion and helplessness experienced by the parents in the study, resulted in a mean score of 73.60 (SD: 14.75).

Finally, in the Ultimate Meaning subscale, which evaluates the spiritual and religious aspects that contribute to better coping with caregiving, participants scored a mean of 19.03 (SD: 7.32).

The correlations performed (Table 6) between the different subscales of the FMTCS and the ages of both parents and descendants suggest a statistically significant relationship between the age of the descendants and how parents find meaning in their daily lives through caregiving.

Table 6. Age and Age offspring with SWS correlation with FMTCS.

		Age	**Age Offspring with SWS**
Variable	**Categories**		
Provisional Meaning	Spearman correlation	0.105	0.375
	p Value	0.594	0.049
Loss/ Powerlessness	Spearman correlation	-0.046	0.083
	p Value	0.815	0.673
Ultimate Meaning	Spearman correlation	0.163	0.271
	p Value	0.407	0.163
Total Meaning	Spearman correlation	0.067	0.294
	p Value	0.734	0.049

Specifically, significant correlations were found for both the Provisional Meaning subscale (Rs = 0.375, p = 0.049) and the Total Meaning score (Rs = 0.294, p = 0.049). These results indicate that as the affected child grows older, parents tend to experience a greater sense of meaning in their caregiving role.

3.2.1. Associations

The bivariate analysis of the Sense of Caregiving Scale (Table 7) revealed differences in the mean scores across the four subscales, although no statistically significant differences were found for any of the sociodemographic variables studied.

Table 7. Bivariate analysis FMCTS.

	Provisional meaning	**Loss/Powerlessness**	**Ultimate meaning**	**Total meaning**

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Variable	Categories	n	Mean (SD)	p Value	Mean (SD)	p Value	Mean (SD)	p Value	Mean (SD)	p Value
Parental role	Mother	19	72.0 (8.9)	0.383	71.3 (14.3)	0.223	19.4 (7.3)	0.772	162.7 (20.4)	0.595
	Father	9	71.6 (5.2)		78.4 (15.3)		18.3 (7.7)		168.3 (18.9)	
Family type	Nuclear	23	72.2 (7.2)	0.220	76.5 (12.6)	0.138	18.9 (7.4)	0.546	167.6 (17.9)	0.442
	Single-parent	3	66.0 (13.1)		63.7 (21.2)		16.3 (4.5)		146.0 (32.2)	
	Separated parents	2	77.0 (1.4)		55.0 (16.8)		25.0 (9.9)		157.0 (8.5)	
Employment status	CUME Subsidy	3	66.7 (9.1)	0.520	65.0 (8.0)	0.256	18.3 (6.0)	0.402	150.0 (8.5)	0.054
	Unemployment	5	71.4 (7.8)		71.2 (12.9)		14.8 (4.9)		157.4 (11.2)	
	Part time employment	3	68.0 (14.7)		60.7 (25.6)		18.7 (11.5)		147.3 (33.7)	
	Full time employment	17	73.6 (6.2)		78.1 (13.0)		20.5 (7.5)		172.2 (17.4)	
Educational level	Primary	4	76.5 (2.5)	0.564	63.5 (16.5)	0.582	22.2 (11.3)	0.848	162.3 (20.9)	0.708
	Secondary	5	74.4 (2.5)		78.6 (12.9)		18.0 (6.1)		171.0 (8.0)	
	Vocational training	6	70.0 (12.8)		74.0 (18.6)		17.7 (7.6)		161.7 (32.1)	

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	University	13	70.3 (7.0)		74.6 (13.2)		19.1 (6.9)	164.0 (17.1)	
Number of children	1 offspring	4	76,2 (0,9)	0.212	70.5 (25.9)	0.968	19.0 (9.8)	165.8 (17.7)	0.594
	2 offsprings	15	72,5 (8,2)		74.5 (13.8)		19.7 (7.6)	166.7 (23.3)	
	3 offsprings	9	68,8 (8)		73.6 (11.9)		17.9 (6.4)	160.2 (14.7)	
Birthorder of offspring with SWS	First child	7	74,7 (3,1)	0.519	73.6 (22.5)	0.911	23.0 (9.1)	171.3 (22.6)	0.697
	Second child	14	71,6 (9,3)		73.1 (11.7)		17.1 (6.3)	161.9 (20.8)	
	Third child	7	69,4 (7,7)		74.6 (13.3)		18.9 (6.6)	162.9 (15.2)	

SD (standard deviation).

In the Provisional Meaning subscale, higher-than-average scores (mean: 71.85) were observed among: separated parents (77.0), Parents with primary education level (76.5 and parents with only one child (76.2)

The Loss/Powerlessness subscale, which reflects feelings of helplessness and loss of control experienced by caregivers in their decision-making process and caregiving role, showed higher scores in: nuclear families (76.5), parents working full-time (78.1) and fathers compared to mothers (78.4 vs. 71.3)

Regarding the Ultimate Meaning subscale, parents with a higher tendency to incorporate spirituality into caregiving were: separated parents (25.0) and parents whose affected child was their firstborn (23.0)

A similar trend was observed in the Total Meaning score, where:

- Parents whose affected child was their firstborn scored the highest (171.3)
- Nuclear family parents showed a higher sense of caregiving (167.6)
- Parents working full-time had higher total meaning scores (172.2 vs. 150.0–157.4 and 147.3; p = 0.054) compared to those working part-time or unemployed.

3.3. Sense of Caregiving Through Coping Strategies

The correlations between the Sense of Caregiving Scale (FMTCS) and Brief Cope (Table 8) reveal significant associations like parents who exhibit a higher Provisional Meaning which reflects the ability to recognize positive aspects of their situation also demonstrate: greater active coping (Rs =

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0.423; p = 0.025), greater acceptance (Rs = 0.562; p = 0.002) and higher use of humor as a coping mechanism (Rs = 0.557; p = 0.002).

Table 8. Correlation of FMTCS with Brief Cope.

		Provisional Meaning	Loss/ Powerlessness	Ultimate Meaning	Total Meaning
Variable	**Categoría**				
Active coping	Correlación Spearman	0.423	-0.130	-0.177	-0.016
	Valor P	0.025	0.509	0.367	0.936
Planning	Correlación Spearman	0.361	-0.128	0.363	0.159
	Valor P	0.059	0.517	0.058	0.419
Use of instrumental support	Correlación Spearman	0.175	-0.212	0.359	0.026
	Valor P	0.373	0.279	0.061	0.896
Use of emotional support	Correlación Spearman	0.260	-0.084	0.356	0.173
	Valor P	0.182	0.671	0.063	0.378
Self-distraction	Correlación Spearman	0.057	-0.221	0.087	-0.163
	Valor P	0.772	0.259	0.660	0.408
Venting	Correlación Spearman	0.323	0.237	0.259	-0.050
	Valor P	0.094	0.226	0.182	0.800
Behavioral disengagement	Correlación Spearman	-0.142	-0.362	-0.111	-0.401
	Valor P	0.470	0.058	0.574	0.034
Positive Reframing	Correlación Spearman	0.329	0.037	0.387	0.328
	Valor P	0.087	0.851	0.042	0.088
Denial	Correlación Spearman	.0.173	-0.337	0.122	-0.311
	Valor P	0.380	0.080	0.536	0.108
Acceptance	Correlación Spearman	0.562	0.190	-0.041	0.293

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	Valor P	0.002	0.333	0.836	0.130
Religion	Correlación Spearman	0.087	-0.183	0.785	0.209
	Valor P	0.659	0.352	0.000	0.286
Substance abuse	Correlación Spearman	0.096	-0.322	0.287	-0.155
	Valor P	0.628	0.095	0.139	0.431
Humor	Correlación Spearman	0.557	0.091	0.151	0.271
	Valor P	0.002	0.645	0.443	0.163
Self-blame	Correlación Spearman	0.179	0.006	0.572	0.245
	Valor P	0.363	0.977	0.001	0.208

No statistically significant associations were found between Loss/Powerlessness and any coping strategies. In the Ultimate Meaning subscale, which reflects spiritual and religious aspects of caregiving, significant correlations were identified with: positive reframing (Rs = 0.387; p = 0.042), religious coping (Rs = 0.785; p < 0.001) and self-blame (Rs = 0.572; p = 0.001), with the latter reflecting self-criticism and guilt experienced by parents.

Finally, the Total Meaning Score, obtained by summing the three subscales, showed a significant negative correlation with behavioral disengagement (Rs = -0.401; p = 0.034). This suggests that as parents develop a greater overall sense of caregiving, they are less likely to engage in behavioral disengagement, meaning they are less inclined to withdraw efforts or give up on addressing stressors.

4. Discussion

The diagnosis of a rare disease in a child triggers a coping process that may involve feelings of guilt, insecurity, anger, and fear, often exacerbated by a lack of knowledge, which can, in turn, intensify stress levels due to the uncertainty of disease progression [34]. In this study, parents demonstrated an active coping style, accepting both the disease and the care responsibilities for their children. This acceptance led them to take direct actions to manage stressors without resorting to substance use or behavioral disengagement as avoidance mechanisms.

Returning home after hospitalization presents additional challenges for parents of children with rare diseases. Once at home, parents become the primary observers of symptoms, disease progression, and potential complications, including those that may be life-threatening [35]. Consequently, parental education, attitudes, and approaches to newborn care play a critical role in symptom management and disease progression.

Rare diseases exert a profound emotional impact on both the affected individual and their family environment. In the case of newborns, parents experience overwhelming instability, facing a lifelong situation that requires continuous adaptation [36]. Thus, parents need specialized support, particularly during certain critical periods, to help them develop coping strategies and problem-solving skills that facilitate constructive adaptation to their circumstances [37].

Acceptance of the disease, as observed in this study, aligns with previous research on caregivers of individuals with Sturge-Weber syndrome (SWS). A study conducted in the United States and Canada in 2000 [38] found that acceptance develops over time as the affected child grows. Similarly, this study shows that as time progresses, parents begin to adopt additional coping mechanisms, such

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as humor and emotional venting, which allow them to find positive aspects in their situation, foster personal growth, and strengthen emotional resilience. This emotional understanding and empathy enable parents to support and advise others facing similar challenges.

Within this process, nursing professionals are an ideal gear for the training and education for the health of these parents, being necessary to have professionals trained in Sturge Weber Syndrome and its different variants, to be able to perform different interventions both before the convulsive events that the offspring may have, and to control anxiety levels in critical moments, and to provide a better performance with parents, bearing in mind that parents will be very knowledgeable about the disease and will always be present during its affectation in the life of their offspring [39]. In addition, knowing the course of the syndrome, many of those affected will be admitted to hospitalization units in the first months of life, where the coexistence with nursing professionals will be common and the exchange of knowledge regarding care and techniques to be performed will be essential for the improvement of the hospital process. The interventions that nursing professionals can carry out for learning, support, coping, stress reduction or help in the creation of the parent-child bond will be a fundamental pillar [40,41], since early recognition and action will mean an increase in the quality of life and life expectancy of those affected.

These interventions will aim to improve the parents' coping and sense of caring, thus reducing symptoms of caregiver burnout and preventing Burnout syndrome. Burnout syndrome can appear in parents who are caregivers of children with complex needs as described in different articles [42] and it will be essential to curb burnout in the short and long term. Abdoli et al. in 2020, observed that caring for sick children is experienced as a responsibility that cannot be neglected, which can lead to the appearance of this caregiver burnout syndrome [43]. Increasing the supports and services needed by these caregivers of offspring with complex needs, as well as promoting research on rare diseases, will provide them with the opportunity to improve the coping and sense of care that they will exercise over their offspring affected with Sturge Weber Syndrome.

STRENGTH AND LIMITATIONS OF THE STUDY

One of the inherent challenges of studying rare diseases is their low incidence and prevalence, which limits the possibility of obtaining large sample sizes. Despite this challenge, conducting studies with the sample sizes available in these conditions remains crucial.

Another limitation of this study is the higher representation of mothers compared to fathers, which could affect the generalizability of the findings. However, this imbalance aligns with the current socio-cultural reality, where the primary responsibility for caregiving in children with complex needs continues to fall predominantly on mothers [44,45].

As a notable strength, this study represents a pioneering effort in this field, as, to the best of our knowledge, no similar research has been conducted on this specific population.

FURTHER RESEARCH AND RECOMMENDATIONS

It would be highly relevant to replicate this study with parents of children with other rare diseases and/or complex chronic conditions. Such efforts would provide a broader understanding of coping strategies among parents in similar situations.

Future studies should also employ longitudinal designs to track the evolution of coping mechanisms and the sense of caregiving over time. Additionally, multicenter and international studies would help overcome the limitation of small sample sizes by providing a more comprehensive perspective.

Moreover, qualitative research approaches could offer in-depth insights into the lived experiences of parents, contributing a richer understanding of this phenomenon.

The findings of this study can help raise awareness about the realities faced by parents of children with rare diseases and highlight the importance of research in this field. Generating robust evidence is essential to train, educate, reassure, and support parents, guiding them toward constructive coping strategies that enable them to approach caregiving from the most positive perspective possible.

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5. Conclusions

The sense of caregiving among parents increases as their child with Sturge-Weber syndrome grows, allowing them to gradually accept and cope with the reality of the condition. Over time, parents strive to find meaning in their caregiving role, focus on positive aspects, and seek personal growth through their experience with the disease.

Parents feel more fulfilled in their daily lives as they derive meaning from caregiving, particularly after processing the diagnosis and observing their child's progress.

As time progresses, they also begin to adopt additional coping strategies, such as emotional venting, positive reframing, and humor, which further contribute to their emotional resilience and well-being.

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Abbreviations

The following abbreviations are used in this manuscript:

SWS	Sturge Weber Syndrom

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FMTCS	Finding Meaning Through Caregiving Scale
AESSW	Asociación Española de Síndrome de Sturge-Weber
SD	Standard Deviation
IQR	Interquartile Range

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