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Family quality of life and autism spectrum disorder: Comparative diagnosis of needs and impact on family life

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ABSTRACT

Background: Families of children with autism spectrum disorders (ASD) face ongoing challenges that can affect their family life. Helping those families cope with the impact of ASD and promote more positive family and child outcomes requires research to better understand the differential aspects of quality of life for those families.

Aim: This article examined the quality of life of 77 families (n = 45 families with children with ASD aged 0–12 years old, and n = 32 families with other developmental disabilities).

Methods and procedure: The Family Quality of Life Scale (FQOL) was applied.

Outcomes and results: The relationships between importance and satisfaction were analyzed, contrasting differences between families, and studying the influence of age. Results show the presence of common needs, as the higher ratings in importance versus satisfaction evidenced, but also specific and more evident needs in families of children with ASD, motivated by the differential characteristics of the disorder and their environment. Age was relevant to focus support on priority areas.

Conclusion: The need to adapt to family individualities to promote their quality of life was concluded.

Implications: Those findings reinforce the importance of bringing together theoretical knowledge and evaluation of professional practice as a framework for converting the latter into good practices and quality actions.

1. Introduction

The current paradigm of disability emphasizes the importance of support and assistance for people with intellectual and developmental disabilities, focusing the efforts on life contexts to ensure the stimulation, development and learning of the person (Benito & Carpio, 2017; Turnbull, 2003). In the case of children with autism spectrum disorder (ASD), the attention is focused on three essential aspects that can affect them and their family's quality of life: (a) receiving an early diagnosis and specialized early care, (b) having adequate educational and community resources and (c) having a social support network that facilitates inclusion (Vidriales,

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Hernández, Plaza, Gutiérrez, & Cuesta, 2017), their family being the first socializing nucleus.

Knowing that family and individual quality of life do not have to be defined differently (Verdugo et al., 2012), and that the quality of life of families with ASD members presents the same components and factors as that of families with no ASD members (Benito & Carpio, 2017), greater difficulties, fears, concerns, and needs have been observed in families of people with ASD (Canal et al., 2010; Durán, García-Fernández, Fernández, & Sanjurjo, 2016; Poston et al., 2003). There still is a lack of research on the impact of an ASD on quality of family life in terms of their differential characteristics (Critchley, Cuadros, Harper, Smith-Howell, & Rogish, 2021). Therefore, the present study focuses on the quality of family life in families with ASD children, compared with other intellectual developmental disorders, to detect the differential and common demands and needs.

1.1. Family choice, empowerment, and family as a unit of support

Current research points out that family-centered philosophy is more powerful than practice so far focused on an individual and their difficulties (Córdoba-Andrade, Gómez-Benito, & Verdugo-Alonso, 2008; Gràcia et al., 2020; Hassanein, Adawi, & Johnson, 2021; Peralta & Arellano, 2010). Family is key in the teaching of prosocial behaviors and the protection of their children (Orte, Ballester, Pozo, & Vives, 2015), in early care and in supporting the needs and demands of the members of the family unit (Turnbull, Turbiville, & Turnbull, 2000), acting as a vehicle to promote the quality of life of the entire family (Benito & Carpio, 2017; Zuna, Summers, Turnbull, Hu, & Xu, 2010).

Under this view, the Family Quality of Life Model appears as an indicator of the satisfaction of the families with children with disabilities (Zeng et al., 2021), focusing on three nuclear elements: family choice, family empowerment perspectives and the family as a unit of support (Allen & Petr, 1996; Poston et al., 2003). *Family choice* changes the professional-family power relationship, where the former acts as a facilitator and support for the priorities of the latter (Benito & Carpio, 2017; Turnbull et al., 2000), orienting towards their functional *empowerment*, by directing actions towards "getting what you want and need" (Turnbull, 2003, p. 5). The identification of the family's priorities, resources, and demands allows the personal and family plan to be designed (Boehm, 2017; Gràcia et al., 2020), working with the whole *family as a unit of support*.

Achieving individual and family quality of life is a priority aspect of organizations, services and professionals supporting people with developmental disorders in general (Hassanein et al., 2021) and with ASD, in particular (Fernández, Montero, Martínez, Orca-sitas, & Villaescusa, 2015). The differential characteristics of ASD (Canal et al., 2010; Garrido et al., 2015) raise the need to investigate whether the quality of life of those families may be affected differently than others. Only by identifying the priority areas of intervention will it be possible to offer an appropriate professional response that will increase the capacity of families to provide adequate care for their children and lead to better outcomes for the whole family (Critchley et al., 2021; Vasilopoulou & Nisbet, 2016).

1.2. Support, well-being and living resources in families with an ASD member

Quality of life of individuals with ASD and their families depends on the same factors that are important for people with other or without developmental disorders. However, there may be patterns of differentiation that make it necessary to investigate their family adjustment throughout their life cycle (Córdoba & Soto, 2007, cited in Benito & Carpio, 2017), as they are involved in a greater performance of tasks or personal roles that imply a considerable increase in the family members' functions.

Receiving a diagnosis of ASD is a hard blow for the family, followed by a change in attitude, which generates a strong feeling of need for support and adaptation to the new reality (Critchley et al., 2021). Parents start out with the expectation of having a healthy baby who will grow up and become an independent adult and, when that expectation is not met, they must make a readjustment regarding their hopes and plans for the future, and those of their child (Baña, 2015; Cuevas et al., 2018). That implies emphasizing the adaptations required in the environment so that the family can experience satisfaction and well-being (Hsiao, Higgins, Pierce, Whitby, & Tandy, 2017). Stress reduction is one of the variables that allow to improve the life quality of families with ASD children (Hsiao et al., 2017; Wang, Hu, & Han, 2020). Parents of children with ASD present clinical levels of psychiatric distress, particularly anxiety (Shepherd, Landon, Goedeke, & Meads, 2021) and mothers of children with ASD report higher levels of stress than mothers of children with other disabilities (McStay, Trembath, & Dissanayake, 2014).

Turnbull (2003) referred to five fields of action in family quality of life (health and safety, support for the person, family resources, intra-family relationships and parenting) which can be altered in the presence of a member with ASD, as several studies in different parts of the world have confirmed (Balcells-Balcells et al., 2019; Corcoran, Berry, & Hill, 2015; Critchley et al., 2021; Durán et al., 2016; Garrido, Carballo, Franco, & García-Retamero, 2015; Godoy, Manghi, Soto, & Aranda, 2015; Gorlin, McAlpine, Garwick, & Wieling, 2016; Jones, Bremer, & Lloyd, 2017; McStay et al., 2014; Ortiz-Quiroga, Ariza, & Pachajoa, 2018; Shepherd et al., 2021; Wang et al., 2020; Zeng et al., 2021).

With regard to health and safety (physical and emotional health, access to health care tailored to individual needs, and access to safety), aggressive behaviors in a child with ASD due to an alteration in his/her communication (e.g., not differentiating between affectionate and violent actions, such as using fists as a sign of affection instead of giving a hug), can lead to a family situation of physical and emotional insecurity due to the feeling of inability to maintain control (Gorlin et al., 2016).

Regarding support for the person with ASD by extended family or people from the near environment, the lack of understanding (or even acceptance) of the child's behavior can generate a response of social isolation (Gorlin et al., 2016), by not understanding his/her needs or feelings, or by misinterpreting his/her demand behaviors (Durán et al., 2016; Garrido et al., 2015; Godoy et al., 2015).

In terms of family resources, although parents' physical and health problems (Critchley et al., 2021; Shepherd et al., 2021) and a greater need for professional training (Gràcia et al., 2020) and support (Balcells-Balcells et al., 2019; Brun, 2013), the presence of

internal and external family resources that act as protective factors (strength of the family unit, level of marital support, perception of social support.) is also recognised (McStay et al., 2014).

In connection with this are the intra-family relationships, a topic widely related to parental stress (Durán et al., 2016; Hassanein et al., 2021; Hsiao et al., 2017; McStay et al., 2014; Shepherd et al., 2021). As Zeng et al. (2021) pointed out, “family is a dynamic, interconnected and interacting set of relationships” (p. 599), but the communicative difficulties (verbal and non-verbal) of childhood with ASD can be a brake on family-child communicative interactions (Jones et al., 2017).

This leads to the last of the dimensions proposed by Turnbull (2003): parenting. Frustration and confusion are feelings that emerge in the families of people with ASD due to the unexpected behaviors of the child, leading parents to reflect on their caregiving efforts (Corcoran et al., 2015; Hsiao et al., 2017; Zeng et al., 2021). To that can be added the feeling of isolation or disconnection from your child, or the feeling of not stimulating them correctly (Gorlin et al., 2016). That can be aggravated by an uneven distribution of parental responsibilities, where the weight falls on one of the two parents (usually on the mother), which can lead to physical and emotional consequences for the person, as well as to the destabilization of family dynamics (Ortiz-Quiroga et al., 2018; Wang et al., 2020).

Based on this five-domains proposal, Zuna et al. (2010), Zuna, Turnbull, and Summers (2009) reviewed the concept and definition of the family quality of life and concluded that it represents a dynamic state that reflects the well-being experienced collectively and subjectively by family members, which should be assessed to offer families the services and support that allow them to meet their needs at different times.

1.3. The current study

Thus, the objective of this study was to assess the family quality of life in the presence of a child with ASD or other developmental disabilities, to detect the demands and differential needs of those two groups, using the Family Quality of Life Scale (FQOL), originally developed by the Beach Center on Disability (Poston et al., 2003). More specifically, it was intended to describe the quality of family life of children with ASD (Group 1) and with other neurodevelopmental disorders (Group 2), based on the assessment of its dimensions; to identify the presence of differences between groups in relation to the degree of importance and satisfaction given to each dimension of family quality of life; to examine, in each group and between groups, the relationship between the importance given to the dimensions of quality of life and the satisfaction experienced in them; and, finally, to check the influence of the child's age on the families' assessments of their quality of life.

2. Material and method

2.1. Participants

The study consisted of $N = 77$ families ($n = 45$ mothers, 58.4%; and $n = 32$ fathers, 41.6%) of children aged 1–12 years ($M = 7.26$, $SD = 2.82$), with ASD and other developmental disabilities. The sample was divided into two groups: Group 1, consisting of $n = 45$ families of children with ASD aged 1–12 years ($M = 7.11$, $SD = 3.05$), and Group 2, composed of $n = 32$ families with children with other developmental disorders (ADHD, emotional disorders, hearing impairment, specific learning disabilities, intellectual disability, specific language disorder, etc.) aged 1–12 years ($M = 7.47$, $SD = 2.49$).

2.2. Instrument

The Family Quality of Life Scale (FQOL) is an instrument composed of five dimensions (family interaction, parental role, health and safety, general resources, and support for the person), each with eight items (except for *Family interaction* with nine), making a total of 41 items. They are valued on a 5-point Likert scale (1: very dissatisfied/very unimportant; 5: very satisfied/crucial importance) on two axes: importance and satisfaction. The factorial structure of the scale was tested on several occasions (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Park et al., 2003; Poston et al., 2003).

In this study, in terms of the reliability and stability of the measures, all the coefficients were statistically significant ($p < .001$), ranging from $r = 0.48$ – 0.68 in importance and $r = 0.46$ – 0.77 in satisfaction. The overall coefficients of the Scale of both importance ($r = 0.68$) and satisfaction ($r = 0.77$) allowed to verify an adequate temporal stability. In relation to internal consistency, the scores on the correlation corrected index for importance were between 0.42–0.69%, and 56% of those scores were above 0.60. Therefore, according to the discrimination index (DI), most of the items highly discriminated the trait that was intended to be measured: the family quality of life. Cronbach's Alpha index for the total scale showed excellent internal consistency in importance ($\alpha = 0.95$) and satisfaction ($\alpha = 0.937$).

2.3. Information analysis

A descriptive study of the dimensions of the FQOL was carried out through measures of central tendency and deviation to find out the importance and satisfaction with the family quality of life in the two contrast groups. Subsequently, non-parametric inferential statistics (Wilcoxon signed-rank test and Mann-Whitney U test) were used, given the non-compliance with the assumptions of normality (Kolmogorov-Smirnov test $p < .001$) and equality of variances (Levene test $p > .001$). A 95% confidence interval ($p < .05$) was considered to estimate the significance of the differences.

3. Results

Below are presented the results of three analyses: of the quality of life experienced by families of children with ASD (Group 1) and with other developmental disabilities (Group 2), of the relationship between importance and satisfaction experienced by both groups and the contrast between them, as well as of the study of the influence of the child's age as a factor that affects the assessments of the family quality of life.

Fig. 1 presents the analysis of the values of central tendency and dispersion. In the first place, it shows that in both groups of families, the scores in importance were higher than those in satisfaction in all dimensions. In Group 1, that was more noticeable in *support for the person*, where the mean difference was 1.81 points, and it was the least valued dimension at the level of importance ($M = 4.31$, $SD = 1.21$) and, above all, in satisfaction ($M = 2.5$, $SD = 1.29$). In Group 2, the greatest imbalance between importance and satisfaction occurred in *general resources*, with a differential average of 0.87 points. Overall, the differences between importance and satisfaction were greater in Group 1 (greater than 1 point, except for *family interaction*) than in Group 2 (between 0.46 and 0.87 points). On the contrary, the differences in standard deviations between importance and satisfaction were lower in Group 1 compared to Group 2, demonstrating a greater concentration or homogeneity in the responses of families of children with ASD (see Fig. 1).

Data in Fig. 1 have also shown that, in both Group 1 (G1) and Group 2 (G2), the dimensions considered most important were *health and safety* (G1: $M = 4.61$, $SD = 0.78$; G2: $M = 4.56$, $SD = 0.82$), in which the subjects expressed moderate (G1: $M = 3.46$, $SD = 0.8$) or high satisfaction (G2: $M = 4.04$, $SD = 0.93$), and *family interaction* in importance (G1: $M = 4.56$, $SD = 0.82$; G2: $M = 4.83$, $SD = 0.38$) and satisfaction (G1: $M = 4.04$, $SD = 0.93$; G2: $M = 4.2$, $SD = 0.59$).

The statistical significance of those differences in Group 1 was verified through the Wilcoxon signed-rank test, in favor of importance versus satisfaction in *parental role* ($Z = -2.121$, $p < .032$), *health and safety* ($Z = -2.333$, $p < .033$), *general resources* ($Z = -2.264$, $p < .016$) and *support for the person* ($Z = -2.83$, $p < .001$), but not in *family interaction* ($Z = -2.24$, $p = .181$). In Group 2, statistically significant differences were also found in *family interaction* ($Z = -2.33$, $p < .036$), *health and safety* ($Z = -2.24$, $p < .032$), and in *general resources* ($Z = -2.12$, $p < .05$).

The contrast between groups revealed that the mean values of Group 1 in each dimension were lower than those of Group 2, especially in relation to the *support for the person*, where Group 1 was almost half an average point below, with a greater dispersion, and in *general resources*, with a difference of 0.35 points on average. However, Group 1 had greater variability of responses. The Mann-Whitney U test verified the statistical significance of the differences in satisfaction, in favor of Group 2 ($p < .05$; $p < .001$), but not in importance (see Table 1).

Table 2 presents a more detailed analysis of the items of each dimension in relation to family satisfaction.

Finally, the differences according to the child's age were checked. There was a general decrease in the importance given to the dimensions of quality of family life (except for *support* in Group 1) in relation to the age of the family member with ASD or other

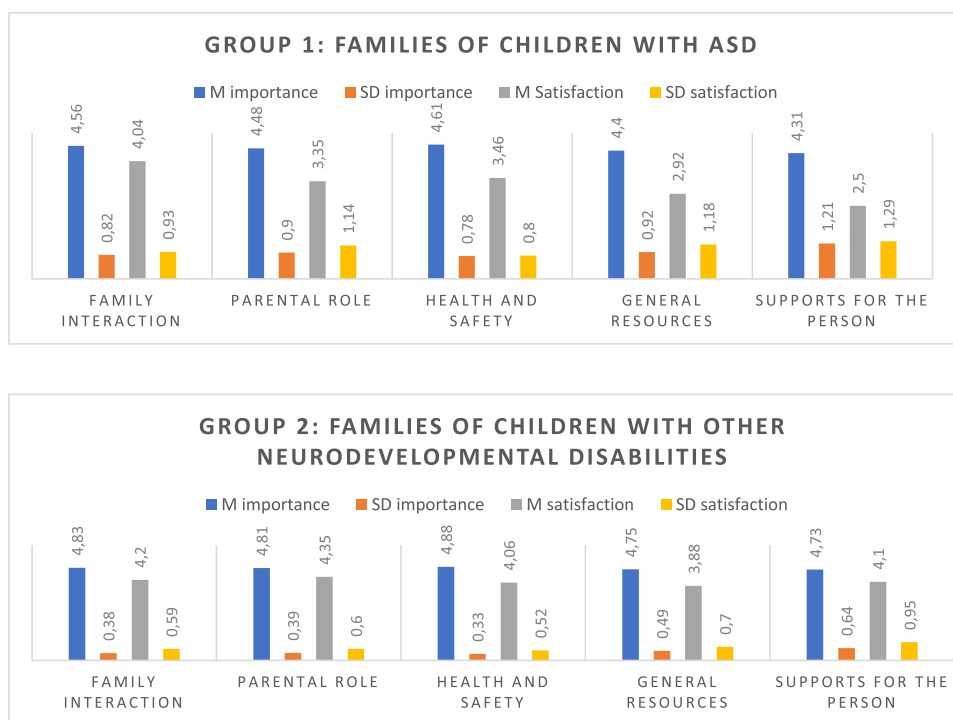


Fig. 1. Means and standard deviations by dimensions of the quality of family life in a group of families with children with ASD (Group 1) and with other neurodevelopmental alterations (Group 2).

developmental alterations. In terms of satisfaction, while in Group 1 the ratings of all dimensions (except for *family interaction*) increased, in Group 2 there was a decrease (see Fig. 2).

The Mann-Whitney U test confirmed that, in many cases, the differences were statistically significant ($p < .05$). In Group 1, the importance given to the items by families of children with ASD aged 0–6 years was higher than that given by families with children aged 6–12 years, especially in the items *health and safety* (mean difference of 1.75 points; $p < .001$), *parental role* (mean difference of 0.98, $p = .032$), *general resources* (mean difference of 0.625, $p = .08$) and *family interaction* (mean difference of 0.223, $p = .11$). In the case of *support for the person*, the importance given by families increased significantly with the age of the child (mean difference 0.709, $p < .001$). Satisfaction with the dimensions of quality of life increased significantly in families of children with ASD (except in *family interaction*, in which a decrease of 0.04 points was observed, not significant). They highlighted the dimensions of *support for the person*, which increased by 1.38 points ($p = .021$); *parental role*, which increased by 1.29 points on average ($p = .024$); *general resources*, which increased by 1.17 points ($p = .033$); and finally, *health and safety*, with a rise of 0.75 points ($p = .13$).

In Group 2, the importance given by families to the dimensions of family quality of life decreased (as in Group 1), although not significantly ($p > .05$). Satisfaction was significantly higher in the case of families of children with neurodevelopmental disorders aged 0–6 years, compared to those aged 6–12 years, in almost all dimensions: *general resources* (difference of 1 point, $p = .035$), *health and safety* (difference of 0.99 points, $p = .048$), *parental role* (difference of 0.88 points, $p = .032$), *family interaction* (difference of 0.814, $p = .048$), but not in *support for the person* (difference of 0.58 points, $p = .51$).

4. Discussion

Families are the primary social group of all people, regardless of their origin and condition. They are also the primary social group of people with ASD and with other developmental disabilities. The capacity of those families to create opportunities and adapt to the demands of education throughout the different stages of the child's life cycle is associated with the quality of the family's relationships with their environment, reinforcing social support systems, minimizing stress factors and strengthening the ability to meet daily challenges effectively.

The deficit model viewed families with members with ASD or other developmental disabilities as *disabled*, lacking coping skills, experiencing poor physical and social well-being, and feelings of guilt. Those families were considered by many professionals as different from the families of children without developmental alterations (Badia i Corbella, 2005; Ortiz-Quiroga et al., 2018). In contrast, the new paradigm of disability pays special attention to covering the needs of the family unit, as a key to improving the life of the person with developmental disorders (Balcells-Balcells, Giné, Guàrdia-Olmos, Summers, & Mas, 2019; Hoffman et al., 2006). That is reflected in the high evaluations that the families of this study gave to the dimensions of their quality of life both in importance and satisfaction.

All the same, a certain lack of correspondence between importance and satisfaction was found in both groups of families with regard to their quality of family life. Specifically, families of children with ASD highlighted the *health and safety* dimension as the most important but were not satisfied with it. More notable was the difference found in the dimension of *support for the person*, which was also the worst valued one in terms of satisfaction. A remarkable finding in that same group was their assessment of *family interaction* because, in addition to being placed second as the dimension of greatest importance, it was the one that obtained a less notable difference with respect to satisfaction.

Previous studies obtained an equivalent result when applying the family quality of life scale in other contexts (Bello-Escamilla, Rivadeneira, Concha-Toro, Soto-Caro, & Díaz-Martínez, 2017; Córdoba-Andrade et al., 2008; Lumani & Córdoba, 2014; Ortiz-Quiroga et al., 2018). At the earliest stage of childhood development with neurodevelopmental impairments, the family importance given to improving the quality of the parent-child relationship (Baña, 2015) overlaps with the relevance given to supports which could be justified because, at first, the focus of families' demands is on receiving training and information to know how to support their children (Balcells-Balcells et al., 2019), rather than on claiming institutional support, and from health and safety services.

When assessing the *support for the person*, discrepancies were found between families, determining the families of children with ASD as less satisfied. This may be because the support offered to their child is excessively generic and does not take into account that "all families are different from each other and, although those families may share similar experiences, not all face this event in the same way" (Badia i Corbella, 2005, p. 333). That way, the differential nature of each alteration and the needs to offer individualized attention are being forgotten. What those differences indicate is the need and demand to ensure quality of family life adapted to the

Table 1

Differences between groups in the dimensions of Family Quality of Life depending on the importance and satisfaction.

Dimension	Importance					Satisfaction				
	Diff M	Diff SD	Mn G1	Mn G2	U	Diff M	Diff SD	Mn G1	Mn G2	U
Family interaction	-0.277	0.440	4.5	5	2.50	-0.167	0.395	4	4	5*
Parental role	-0.333	0.504	4.5	5	3.00	-1.000	0.534	3	4	6.5**
Health & Safety	-0.188	0.442	4.5	5	3.00	-0.604	0.276	3.5	4	5*
General Resources	-0.355	0.433	4	5	2.50	-0.9583	0.479	3	4	5.5*
Supports for the person	-0.417	0.562	4	4.5	3.00	-1.604	0.338	2.5	4	4**

* $p < .05$.

** $p < .001$.

Table 2
Differences between groups in the items of the dimensions of Quality of Family Life in function of satisfaction.

Dimension	Item	Question	G1			G2			
			M	SD	Md	M	SD	Md	U
Parental role	4	My family members teach children to get along with others	3.5	0.55	3.5	4.33	0.53	4	6*
	6	The adults in my family teach children to make good choices	2.83	1.17	3	4.33	0.52	4	4*
	7	The adults in my family have time to attend to the needs	2.33	1.51	3	4.17	0.75	4	5.5*
Health & Safety	6	My family is served by health entities that know our individual health needs	2.83	0.41	2.5	3.83	0.41	3.5	2.5*
	8	My family does regular medical checkups	3.17	0.41	3	4	0.63	4	5.5*
General Resources	4	My family has outside help so we can take care of the family's special needs	1.67	1.03	2	3.67	0.52	3.5	2*
	7	My family members have friends or others who support us	3.33	0.82	3.5	4.33	0.52	4.5	4*
	8	My family members have some time for us	2.67	0.83	2.5	3.83	0.75	3.5	5.5*
Support to the person	3	My family member with Special Educational Needs (SEN) has support to make friends	2.5	1.38	3	4.17	0.98	4.5	6*
	5	My family has government aid that our family member with special needs.	1.67	1.03	2	3.67	1.03	4	4*
	7	My family gets good medical care for the member with special needs	2.33	1.21	2.5	4.33	0.82	4.5	3*
	8	My family has a good relationship with professionals from health and educational institutions who work with our family member with special needs	2.67	1.51	3	4.5	0.84	4.5	4.50*

* $p < .05$.

particular needs of each family unit.

The *parental role* dimension was also significantly better valued by parents of children with other developmental disorders than ASD. Those families said they felt more satisfied with their role as mediators in relationships with others, in attending to the demands of their children and in supporting decision-making, being also one of the dimensions best valued in previous studies with relatives of children with congenital deficits (Ortiz-Quiroga et al., 2018). Families of children with ASD show greater problems than families of children with intellectual disabilities, due to the difficulties of parents in managing certain behaviors typical of ASD (Canal et al., 2010). The difficulties at the communicative and social level of children with ASD have been negatively related to the family quality of life (Durán et al., 2016), as they generate a feeling of dissatisfaction in families due to not achieving effective communication (Garrido et al., 2015), or even generate stress that is negatively associated with their own involvement in their children's quality of life and their own as family members (Hsiao et al., 2017; Wang et al., 2020). All of that can be aggravated by the fact of feeling responsible for providing primary care to the child throughout their life and not having sufficient knowledge or training to do so (Gorlin et al., 2016). It would also be appropriate to introduce here the debate on the role of each parent in the care of the child with ASD, as several studies have found discrepancies in the assessments that parents make about the priorities in the support and assistance to their children with ASD (McStay et al., 2014; Zeng et al., 2021) or even in the concept of inclusion itself (Losada-Puente, Fiuza, & Baña, 2021), which seems to be reflecting the maintenance of certain traditional care roles attributed to mothers and fathers, which is increased in the presence of a developmental disability.

Families with children with ASD assessed more negatively the treatment in *health and safety services* and their use of them. One of the arguments that justifies that assessment is that there is still a considerable delay in the diagnosis of ASD (Vidriales et al., 2017). Early detection of the disorder, together with early treatment, "can reduce the burden of disease and improve the quality of life of the affected children and their families" (Canal et al., 2010, p. 91). Similarly, the presence of health problems in the person with ASD and the difficulties of access to service to meet family needs have been considered influential factors in the quality of family life (Jones et al., 2017). Those families reported having, to a lesser extent, possibilities to access external support services, as well as having a social support network close to the family, which generates a greater burden of stress compared to other caregivers (Gorlin et al., 2016). That role, generally, falls on the figure of the mother (Córdoba-Andrade et al., 2008; Ortiz-Quiroga et al., 2018).

Despite the importance given to the family-professional bond as a "mediating factor that influences the well-being of the family" and defined in terms of "mutual alliance" (Lumani & Córdoba, 2014, p. 53), in the case of families of people with ASD, many stop trusting professionals and their therapies, stating that they are useless, although at the same time, they do not stop trying new therapies because they consider that they could not forgive themselves for stopping trying (Brun, 2013). Professionals must attend to the needs of the person and their family and "establish links with the entities and services of the community that offer training and learning opportunities" (Pallisera, 2020, p. 131), since having access to a diversity of human and material resources, of a specific or general type, helps them and their family member with disabilities to live better (Fernández et al., 2015; Hassanein et al., 2021).

Finally, in this study, the child's age was decisive in the importance given by families to their quality of life and their satisfaction with it. It contrasted with previous studies in which the presence of differences based on that variable was rejected (Córdoba-Andrade et al., 2008; Lumani & Córdoba, 2014; Ortiz-Quiroga et al., 2018). In the present study, families with younger children placed more importance on all dimensions of family quality of life than those with older children. With the increase in chronological age in childhood with developmental disabilities, the child's independence and self-care increases, thus reducing the need for help from families (Córdoba-Andrade et al., 2008). An exception was the case of families of children with ASD in relation to the *support* dimension, which was significantly more important for those with children when 6–12 years old. It may be because of the "process of adjustment and adaptation" (Badia i Corbella, 2005, p. 333) experienced by families, being at first themselves the ones who take control and responsibility to cover the most obvious needs of their children, but later delegating this responsibility to services and support systems that meet the needs of the person (although they do not do it with those of family unit). Along those lines, Summers et al. (2007) concluded that families were satisfied with the amount of support and services offered to their child, although not with

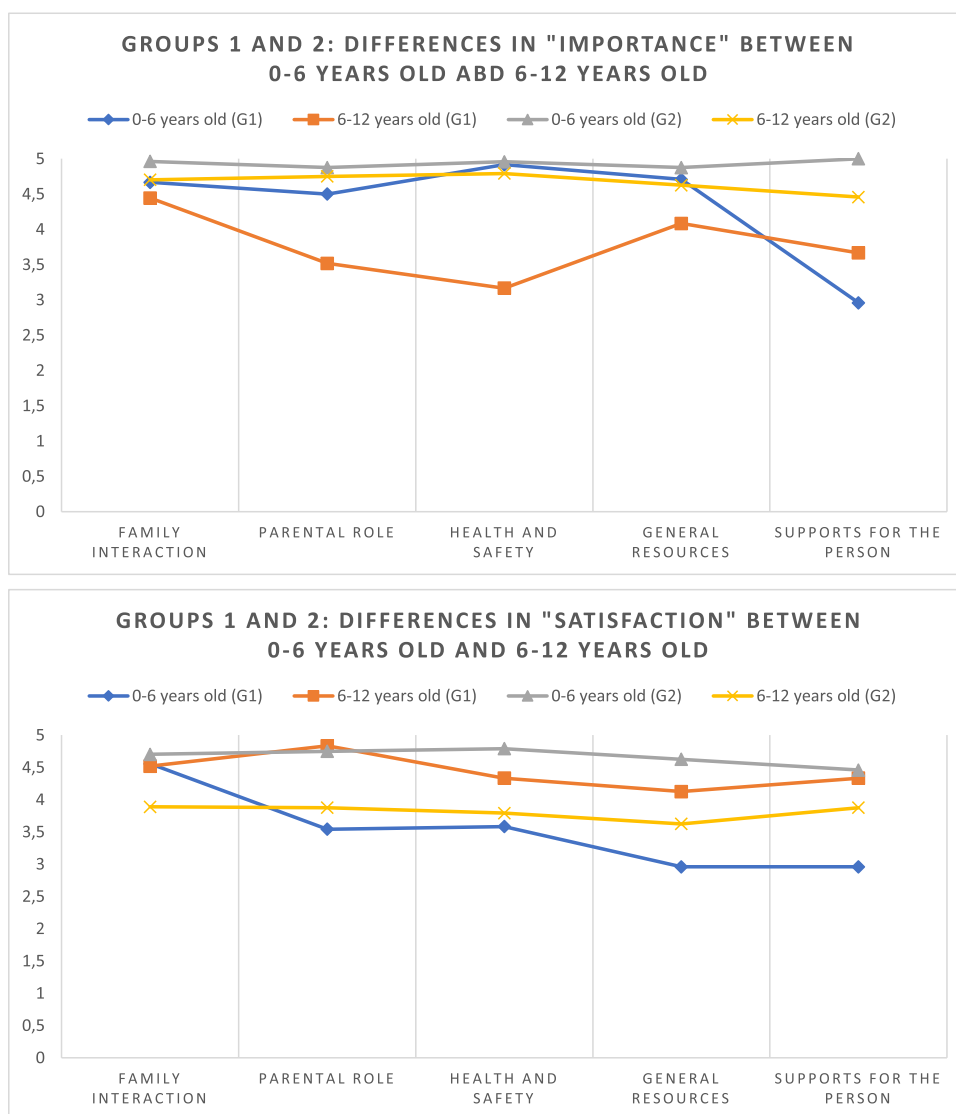


Fig. 2. Evolution of the assessments of the quality of family life dimensions in a group of families with children with ASD (Group 1) and with other neurodevelopmental disorders (Group 2) depending on age.

those provided to the family unit.

Regarding satisfaction, there were conflicting results between groups in relation to age. While satisfaction was generally increasing in families of children with ASD (significant for the *support*, *parental role*, and *general resources* dimensions), in families in which there was a member with another neurodevelopmental disorder, there was a worsening in those assessments, which was significant in all dimensions except for *support*. The greater satisfaction experienced by families of children with ASD of older ages may be related to a better professional response because “professionals are likely to have doubts about how to better apply and interpret the diagnostic criteria in young children” (Canal et al., 2010, p. 92). There are even studies that corroborate the need for more professional training so that the professionals can feel comfortable with their actions and adapt to the individual needs of the child and family (Gràcia et al., 2020). Along with that, also a greater and better knowledge of families, in addition to a greater adaptation to their parental role are demanded (Badia i Corbella, 2005; Bello-Escamilla et al., 2017). Even so, this contrasts with McStay et al. (2014), who found that mothers’ perceptions of the quality of services worsened as children with ASD got older, indicating higher levels of support in early care.

It seems evident in the light of that data that not only do we have to approach the quality of life of families with ASD members in a similar way to how it is approached in the case of families with members with other alterations of intellectual development, as well as those of families with neurotypical children. What is also evident, is that we must consider the differential characteristics of the disorder and of the families that face the arrival of a child, sibling, or grandchild with ASD.

In that sense, the data related to age and the differences noted between families with children from 0 to 6 years and 6 to 12 years

reflect a process of adaptation to this reality (Badia i Corbella, 2005; Canal et al., 2010). Thus, the needs of the families of the youngest are more focused on achieving a better interaction with their children, on providing them with general and specific health and safety resources, and also on the parents' own role as parents; while families of children from 6 to 12 years old give priority to supporting the person.

5. Conclusions

The different perceptions of the quality of life and the variables of each family at the contextual (situation, relationship of forces, state of acceptance) and personal (effort, belief, satisfaction, conviction) level are affected by everyday situations of one's own life. Difficulties unrelated to the person with developmental disorders, to their life and to their educational/experiential future will influence the capacity of the families themselves for development, learning and quality of family life, and that must be considered when it comes to their attention for the quality of life. Thus, it is possible to highlight some interesting conclusions about research and practice in quality of life of families of children with ASD.

In the first place, the field preoccupied with people with developmental alterations is experiencing a process of change in many ways. The rapid emergence of new paradigms and models has made it difficult to assimilate transformations, which are influencing the quality of life of people with ASD and their groups of coexistence. There is still much to be done, and research is the most appropriate way to ensure optimal evolution by providing rigorous knowledge that theory, research and scientific knowledge can incorporate by analyzing professional practices to turn them into good practices and quality actions.

Secondly, organizations, services and professionals supporting people with ASD should prioritize the family training process, based on the assessment of their needs, demands and potentialities as a unit (Zuna et al., 2009), and focusing their responses on two main components: the participation of all members of the family unit as main actors, and the commitment to transform community ecology in a way that contributes to improving the quality of life of families (Turnbull, 2003). As Gràcia et al. (2020) pointed out in reference to studies carried out in Spain, many families have resigned themselves to adopting the passive role of information receivers, instead of adopting an active attitude, feeling empowered and contributing to professional intervention through activities carried out at home. The participation of the family members implies conceiving of the person with diversity as an active part of the family's and community's ecological environment and analyzing what is important for the family as a whole in terms of quality of life in its various dimensions (Peralta & Arellano, 2010).

To achieve that, the evaluation of the quality of individual and family life becomes a benchmark in the field of intellectual development alterations, as a principle that guides the interventions and practices that are developed through services and programs (Bello-Escamilla et al., 2017; Fernández et al., 2015). It is essential to have an adequate measure of quality of life when what is being studied is the family (Hoffman et al., 2006). The use of the FQOL in the form of a self-report has been a very useful resource for parents to better understand the influence of the aspects contained in the FQOL on development, while facilitating their application and impact on the learning and stimulation of their children and, with it, favoring their participation in activities aimed at their self-determination.

To conclude, it should be pointed out that the results obtained in this work should be taken with caution and awareness of their limitations and, above all, of how to overcome those limitations in future research. First, sample size has been an impediment to the generalization of data to a broader set of population. Although the interest is focused on characterizing and deepening the knowledge about the priority areas of a specific family group, subsequent studies will be used to expand and complete the sample of this study. Secondly, despite the adequate psychometric properties of the instrument used, a study incorporating additional qualitative measures of the family quality of life could improve the understanding of the phenomenon. Thirdly, and in light of the studies reviewed so far, a study focused on the role that fathers and mothers play in the upbringing of their children with ASD seems relevant, as well as incorporating other variables of interest (sociodemographic status, type of family and number of members, type of schooling, etc.). Finally, in order to not only collect data, but also to promote change and improvement in the lives of families, an interesting proposal stemming from this work would be to create joint spaces for shared reflection with families and with professionals in the social, educational and health fields.

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Research involving Human Participants and/or Animals

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CRedit authorship contribution statement

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by Manoel Baña, Luisa Losada-Puente, and María Fiuza. The first draft of the manuscript was written by Manoel Baña and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Informed consent

All data were collected with prior informed consent from the families. No information has been included that would infringe on the right of families and their children to have their information treated confidentially, nor have identifying data of any kind been used. The anonymity of the information contained in the manuscript has been guaranteed.

Disclosure of potential conflicts of interest

All authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest or non-financial interest in the subject matter or materials discussed in this manuscript.

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