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RELATIONSHIP BETWEEN PARENTAL PERCEPTIONS, FAMILY INCOME AND SUPPORT RECEIVED WITH FAMILY QUALITY OF LIFE IN FAMILIES WITH A CHILD WITH AN INTELLECTUAL DISABILITY

Relación entre las percepciones parentales, ingresos familiares y apoyo recibido con la calidad de vida de las familias con un niño o niña con discapacidad intelectual

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Abstract: Research has shown that families raising a child with intellectual disability (ID) face many challenges and need to implement adaptation strategies. Some authors suggest that positive parental perceptions and perceived control could reduce emotional impact and promote family wellbeing. Nevertheless, there are few studies about the relationship between parental perceptions and family quality of life (FQoL) in those families. In this study, we used data from a sample of 251 Spanish parents whose children have ID. Positive perceptions scale and control perceptions scale, Spanish FQoL scale under 18 years-old and a sociodemographic questionnaire were administered to those families. The results of bivariate analysis showed that some dimensions of positive perceptions were related to different areas of FQoL, for example, social inclusion and family accommodation. FQoL was associated with family income and support received. To predict the FQoL level, a multivariate linear regression analysis was conducted. Results indicated that FQoL scores can be predicted by a linear combination of positive perceptions and family income. Practical implications for promoting FQoL in these families are discussed.

KEYWORDS: intellectual disability; family quality of life; positive perceptions; perceived control; family income; support received.

RESUMEN: La investigación ha demostrado que las familias con niños/as con discapacidad intelectual (DI) se enfrentan a muchos retos y necesitan utilizar estrategias de adaptación. Algunos trabajos sugieren que las percepciones parentales positivas y el control percibido pueden reducir el impacto emocional y promover el bienestar familiar. No obstante, existen pocos estudios sobre la relación entre las percepciones parentales y la calidad de vida familiar (CdVF) en estas familias. Utilizamos una muestra de 251 madres y padres cuyos/as hijos/as presentan DI. Se administraron a las familias escalas de percepciones positivas y percepciones de control, la escala española de CdVF para menores de 18 y un cuestionario sociodemográfico. Los resultados del análisis bivariante mostraron que algunas dimensiones de las percepciones positivas estaban relacionadas con diferentes áreas de la CdVF (inclusión social y acomodación familiar). La CdVF se asoció con los ingresos familiares y el apoyo recibido. Para predecir el nivel de CdVF, se realizó un análisis de regresión lineal multivariante. Los resultados indicaron que las puntuaciones de CdVF pueden predecirse mediante una combinación lineal de percepciones positivas e ingresos familiares. Se discuten las implicaciones prácticas para promover la CdVF en estas familias.

PALABRAS CLAVE: discapacidad intelectual; calidad de vida familiar; percepciones positivas; control percibido; ingresos familiares; apoyo recibido.

1. Introduction

THE LITERATURE shows that families play a key role in children's development and supply learning experiences during childhood that are linked to the child's developmental outcomes. This is also true in families with children with intellectual disability (ID) (Davys *et al.*, 2017). The family is the environment that enables individual members to develop and grow effectively. Therefore, the role of families is crucial, especially when children have disabilities or are at risk of them (Festante *et al.*, 2019).

Research on children with disabilities has suggested that having a child with ID may produce negative reactions in the family, and this reduces the potential of family members to foster the child's development (Hastings, 2003; Hu *et al.*, 2012; Malhotra *et al.*, 2012). Many parents caring for children with a disability report high levels of anxiety, depression and stress (Al-Qaisy, 2012; Hayes and Watson, 2013; Keller and Honig, 2004; Lee, 2013). Similarly, it has been found that parents of children with ID generally have higher levels of anxiety, depression and stress than parents of children who develop normally (Baker *et al.*, 2020; Eisenhower *et al.*, 2005; Emerson *et al.*, 2006; Giallo *et al.*, 2015; Oelofsen and Richardson, 2006; Singer, 2006). Some authors found that high parenting stress contributed to the development of more behavioral problems (Baker *et al.*, 2003), lower social competence levels (Guralnick *et al.*, 2006) and more difficulties in the relationship between parents and their child, which resulted in offering them poorer learning development opportunities (Hayes and Watson, 2013). In addition, high stress levels could increase anxious and depressive symptomatology (Keller and Honig, 2004; Singer, 2006), concern parents about how to connect with their child and cause a feeling of incompetence (Guralnick *et al.*, 2008). Therefore, families with children with ID may need to implement a series of adjustment strategies to raise their child, especially during the early years. The experience may cause some difficulties that will impact on the family's emotional wellbeing (Kim *et al.*, 2020; Summers *et al.*, 2005).

Early and second childhood are obviously very different from adolescence in terms of the great influence that the family has on the development of children, for example, in the acquisition of habits and routines, cognitive and social skills, etc. For this reason, we considered it appropriate to focus only on these early ages, unlike previous studies (Ferrer *et al.*, 2017). These routines provide structure, a sense of security and opportunities for emotional connection between parents and children (Crespo *et al.*, 2013). However, for families of children with ID, it is more difficult to establish useful routines (Rodger and Umaibalan, 2011) and caregivers must make greater efforts. These day-to-day difficulties can adversely affect the emotional well-being of families.

Disability studies have changed significantly in recent years, to develop a more positive approach. Research has incorporated a more positive perspective of families of children with ID, with inputs from positive psychology theories (Blacher *et al.*, 2013). We know that families of children with ID will have to cope with the disability diagnosis and adjust to the situation, often dealing with high levels of stress throughout life. However, some families will be able to adjust better to this situation than others and will present higher levels of individual and family well-being (Meirsschaut *et al.*, 2010). Some studies suggest that caregivers' perceptions constitute a relevant predictor of adjustment (Pozo *et al.*, 2006; Pozo *et al.*, 2014; Saloviita *et al.*, 2003). Other studies have found that parents with positive perceptions of their child with ID are more capable of showing feelings of joy, family warmth and personal growth, as opposed to those with further negative perceptions (Fox *et al.*, 2002; Kim, 2001; Ylvén *et al.*, 2006). Some authors have reported that positive perceptions could work as a mechanism for coping with the stress of parents caring for a child with ID (Hastings and Brown, 2002; Lloyd and Hastings, 2008), as these positive perceptions can cushion the emotional impact and foster more well-being in the family (Kayfitz *et al.*, 2010). In fact, predictive models of the psychological adaptation of families who have a child with autism spectrum disorder (ASD) have shown that positive perceptions can predict anxiety (Samios *et al.*, 2012), parental stress and anxiety (García-López *et al.*, 2021; García-López *et al.*, 2016) and depression and anxiety (Lovell and Wetherell, 2020). Positive perceptions likely promote a closer, more affectionate relationship between parents and their child, which helps to build developmental outcomes in children with ID (Innocenti *et al.*, 2013).

In the context of parental perceptions, perceived control by caregivers of children with ID is another key element related to family well-being. Parents who perceive greater control over decisions and strategies concerning their child with ID show better adjustment levels (Hastings and Brown, 2002; Jones and Passey, 2005; Lanfranchi and Vianello, 2012). As parents, feeling more in control of the interventions that their child receives and the decisions that need to be made regarding his/her care provides more parental satisfaction and less psychological distress (Hill and Rose, 2009).

However, family systems theory (Seligman and Darling, 2007) emphasizes the dynamic, interdependent nature of the family unit, with the experiences of one member potentially affecting the entire system. Thus, a theoretical systemic-ecological approach in families of children with ID is growing among the scientific and professional community and is developing into the study and conceptualization of family quality of life (FQoL) of families of individuals with disabilities (Hu *et al.*, 2012; Summers *et al.*, 2005). Many authors have studied FQoL despite the initial lack of a more solid, general conceptual framework, which hindered the systematization and provision of valid data in FQoL research (Chiu *et al.*, 2013). After a synthesis of previous research, Zuna *et al.* (2010) proposed a definition of FQoL that considered the family as a primary development context and emphasized the importance of accompanying families to enhance this FQoL. This definition highlights the interaction between family characteristics and dynamics, and those of each family member. Family support services and practices act as mediating variables of the effects that the family unit or each family member's characteristics have on FQoL (Zuna *et al.*, 2010). A meta-analysis by Dunst Trivette and Hamby (2007) concluded that the effectiveness of family services is determined by the level of improvement in the FQoL. Support services could help to improve FQoL (Eskow *et al.*, 2011).

Therefore, we cannot ignore the fact that the existence of parental positive perceptions and perceived control will contribute to the FQoL outcome (Seo *et al.*, 2016; Yoon and Kim, 2015). According to Ferrer *et al.* (2017), families with higher positive perceptions and perceived control of their son/daughter with ID and his/her environment could have a greater FQoL. In this respect, Bayat (2007) found a significant association between the presence of positive perceptions of children with ASD and their FQoL levels. According to the author, positive perceptions improve family closeness and feelings of compassion, and provide a more positive outlook on life, patience and personal empowerment. However, there are still not many studies that assess the relationship between positive perceptions, perceived control and FQoL in families of children with ID.

Previous research has revealed several individual and family variables that are related to FQoL. Family income has a positive relationship with perceived FQoL

(Ferrer *et al.*, 2017; Mas *et al.*, 2016; Meral *et al.*, 2013; Schlebusch *et al.*, 2017). Thus, those studies have found that families with a member with ID have lower FQoL when their family income is lower. In addition, low family income is associated with multiple impacts on family outcomes. This suggests that there is a need to offer support above all to people and families with low family income.

Wang *et al.* (2004) found that maternal satisfaction ratings of FQoL, as characterized by parenting satisfaction, family interactions, physical/material well-being, emotional well-being and disability-related support, increased as a function of family income. However, family employment status appears to be a controversial variable. In some studies, the fact that parents work outside the home is related to better FQoL (Giné *et al.*, 2015). However, Meral *et al.* (2013) found that employment status was not significantly correlated with FQOL.

Families who have to raise a child with ID may need additional and often emotional or direct personal support. However, this support is not always available. People from low socioeconomic backgrounds, for instance, often find it difficult to take advantage of formal support, either because they do not know how to access services or because the system itself creates many barriers to accessing them (Khanlou *et al.*, 2015). As a result, these families often have little time for leisure, which is frequently not a priority for policy and support services (Brown *et al.*, 2010). This situation can affect their FQoL.

As we mentioned above, we focused our study on the early and second stages of childhood, since this is a period of time when families have to devote themselves wholeheartedly to the care and attention of children with ID and require a great deal of support as they face these challenges. Very often, they do not receive the specific support they need (Vilaseca *et al.*, 2017).

From our initial hypotheses, we considered that positive perceptions and perceived control in parents of children with ID aged 1 to 12 years would be significantly related to their FQoL. FQoL is greater the higher the positive perceptions and perceived control levels. In addition, sociodemographic variables of children or their parents may help to predict positive perceptions and perceived control levels.

This study had two main goals. The first was to assess the relationship between parental positive perceptions, perceived control and FQoL among a sample of parents of children with ID aged 1 to 12 years old. The second was to predict FQoL level from a multivariate model including positive perceptions, perceived control and demographic variables, which had shown a statistically significant bivariate relationship with FQoL.

2. Materials and Methods

2.1. *Participants*

The sample was composed of 251 families with children with ID between 1 and 12 years of age ($M = 7.1$, $SD = 3.2$). It was collected through the services that attend the children (mainstream schools, special schools or early intervention centers). We considered two inclusion criteria: participants had to be the primary caregivers of children up to 12 years of age and their children had ID.

Most of the primary caregivers were women (76.1 %) with a mean age of 40.4 years old (*SD* = 7.2). The mean age of men was 43.1 years old (*SD* = 7.7). All participants were resident in Spain. More than half were in active employment (37.5 % working full time and 18.7 % part time), while 42.2 % were looking for work or taking care of household chores and childcare. Regarding the level of family income, more than 70 % earned less than 2,320€ per month. According to the Spanish National Institute of Statistics (INE; 2015), Spanish households had an average annual income of 26,299.87€ (2,191.66€ per month). Therefore, a large number of families in this sample were at or below the Spanish average.

A total of 59.4 % of the children were male and 39.4 % female. In terms of age, 47.8 % were up to 6 years old, and 52.2 % were 7 to 12 years old. The degree of ID was mild (from 33 to 64 %) in 35 %, moderate (from 65 to 74 %) in 27 % and severe (> 75 %) in 33 %. In Spain, the assessment of the percentage of disability is a standardized process carried out by a governmental agency, the Valuation and Guidance Services for People with Disabilities (CAD). In the case of ID, it is graded as mild, moderate and severe. The centers carry out the assessment and establish the degree of disability. A total of 65 % of families had no help with childcare at home. Finally, 95.2 % of parents were very satisfied with the service that their children attended. See Table 1 for more details.

Table 1. Demographic characteristics of family members (n = 251)

Characteristics	% (n)	Characteristics	% (n)
Age of the family member (years)		*Household income (monthly)*	
< 30	5.6 (14)	< 1.200€	27.9 (70)
31-40	41.2 (103)	1.200€ to 2.320€	44.2 (111)
41-50	41.6 (104)	> 2.320€	21.5 (54)
> 51	8.0 (20)	*Support received*	
Missing	3.6 (10)	No	64.9 (161)
Level of education completed		Yes	35.1 (87)
Primary	28.9 (72)	*Services*	
Secondary	35.3 (88)	EIC	25.6 (63)
University degree	37.7 (91)	Schools	65.9 (162)

Employment status		Others	8.5 (26)
Employed full time	37.5 (94)	*Satisfaction level*	
Employed part time	18.7 (47)	1-4	2.4 (6)
Caretaker, household chores	21.9 (55)	5-7	20 (50)
Looking for a job	20.3 (51)	8-10	75.2 (189)
Missing	1.6 (4)	Missing	2.4 (6)

2.2. *Instruments*

We used a brief demographic questionnaire to record family characteristics (parents' age, gender, employment status and household income) and children's characteristics (age, gender, ID level, service that attended to the child, whether families had help with childcare and parental satisfaction with the service).

We used the Kansas Inventory of Parental Perceptions (KIPP) to assess parental perceptions of their child with ID. The original scale was created by Behr, Murphy and Summers in 1992 with four separate scales and 97 items. We used a Spanish version (Ferrer *et al.*, 2015) which is shorter with four scales but only 59 items: Positive Contributions (PCS: with 30 items), Social Comparisons (7 items), Causal Attributions (10 items), and Perceived Control (12 items). In this study, we only used the first and the last scales, which were explicitly designed to assess the positive and control perceptions that parents have regarding their child with ID (Hastings *et al.*, 2005). The PCS has six subscales and seeks to perceive the child with disability as a source of positive contributions in personal and family life (e. g.: *My child is why I met some of my best friends*). And the Perceived Control scale measures the degree of control parents have over their child's management and educational activities in the present and future (e. g.: *How much control do you personally have over managing your child's activities from day to day?*). Items are scored on a 4-point Likert scale (from strongly agree to strongly disagree). The internal consistency of the subscales was adequate. The coefficients of the subscales of PCS ranged from .40 to .83: Source of Happiness and Pride, $\alpha = .83$; Family Strength and Acceptance, $\alpha = .78$; Personal Growth and Maturity, $\alpha = .77$; Sensitivity to Disability, $\alpha = .73$; Expanded Social Network, $\alpha = .72$; Understanding of Life's Purpose, $\alpha = .40$ [64]. The coefficient of the Perceived control scale was .87.

The other instrument we used was the Spanish Family Quality of Life Scales for families with children with ID (Escala de Calidad de Vida Familiar: CdVF-E under 18 years old) by Giné *et al.* (2013). The CdVF-E evaluates seven FQoL dimensions: Emotional Well-Being, Family Interaction, Health, Financial Well-Being, Parents' Organization and Skills, Family Accommodation, Social Inclusion and Participation. It is a self-administered scale with 61 items. The response format is a 5-point Likert scale ("never" to "always") with a "not applicable" option as well. Internal consistency of the overall scale was adequate with a Cronbach's α of .96.

2.3 *Procedure*

Ethical approval was obtained from the Spanish Ethics Committee, which is part of the Network of Ethics Committees in Universities and Public Research Centers in Spain.

To recruit participants, we contacted one of the most important associations in Spain for persons with a disability and their families (Plena inclusión: Confederación Española de Organizaciones en favor de las Personas con Discapacidad Intelectual) and in Catalonia (DINCAT) by letter and telephone and we explained the project. The associations contacted the affiliated early intervention centers, regular schools and special education schools. The coordinators of the centers were asked to help recruit families for the study. Families were informed that their participation would be entirely voluntary and anonymous. They did not receive any financial compensation for their participation. We sent questionnaires to centers all over Spain. Each research pack contained an informed consent form, a demographic questionnaire, the two KIPP scales and the CdVF-E scale. The families had 15 days to fill out the materials and return them to the centers in a closed envelope provided with the protocols. The research packs were returned to the university within a total of 30 days.

2.4. *Data analysis*

IBM SPSS Statistics (version 26.0 for Windows) was used for all statistical analyses. The characteristics of the families and children, and the degrees of the main variables, were analyzed through descriptive statistics (frequency, percentage, mean and standard deviation). To assess the relationship between parental positive perceptions, perceived control and FQoL scores, Pearson's correlation coefficients were computed.

The second goal of the study was to predict FQoL from a multivariate model. For this purpose, data were analyzed in two stages. First, a bivariate analysis was conducted to study the relationship between different family variables and the FQoL scores. For categorical family variables, total FQoL scores were compared via independent samples *t*-test (for comparing two means) or One-Way ANOVA (for more than two means), followed by post-hoc pairwise comparisons. Relationships between family variables and total FQoL scores were examined via Pearson's product-moment correlation coefficients (or Spearman's correlation coefficients for ordinal variables).

Secondly, variables whose effect was found to be statistically significant ($p < .05$) in the previous bivariate analyses were included in a multiple linear regression model to predict FQoL scores. Variables were selected applying backward stepwise criteria beginning with a full model and, at each step, eliminating variables from the regression model to find a reduced model that best explained the data. Missing data were handled by pairwise deletion.

3. Results

In this section, we present the results from the PCS subscales, the perceived control scale and CdVF-E scales, and the relationships between them, which are specifically related with the first objective of our study. Table 2 shows the mean and standard deviation of PCS, perceived control and CdVF-E scores for the families who answered those instruments.

The overall mean FQoL was slightly high (*M* = 3.50, *SD* = 1.27). This result is similar to those of studies conducted in Spain (Giné *et al.*, 2013; Giné *et al.*, 2015) where the CdVF-E instrument was used. The "emotional wellbeing" domain scored highest (*M* = 3.90, *SD* = 1.00), while "financial wellbeing" had the lowest mean values (*M* = 2.85, *SD* = 1.43). These results are consistent with previous studies (Brown *et al.*, 2010). The total score of PCS was a little lower than previous studies (Ferrer *et al.*, 2016) (*M* = 2.93, *SD* = .80). The highest scoring subscale was Sensitivity to disability (*M* = 3.32, *SD* = .72) and the lowest was Understanding of life's purpose (*M* = 2.47, *SD* = .94). Finally, the mean of the perceived control scale was 3.11 (*SD* = .74).

TABLE 2. Descriptive statistics of Family Quality of Life Scale (FQoL), Positive Perceptions (PCS) and Perceived Control scores

Subscale	Mean	SD	**Subscale**	***Mean***	***SD***
Emotional wellbeing	3.90	1.00	Source of happiness and pride	2.91	.83
Family interaction	3.71	1.28	Family strength and acceptance	3.12	.71
Health	3.45	1.27	Personal growth and maturity	2.80	.83
Financial wellbeing	2.85	1.43	Sensitivity to disability	3.32	.72
Parents' organization and skills	3.49	1.38	Expanded social network	2.62	.84
Family accommodation	3.56	1.02	Understanding of life's purpose	2.47	.94
Social inclusion and participation	3.63	1.42	PCS total score	2.93	.80
FQoL total score	3.50	1.27	Perceived control total score	3.11	.74

Then, the relationship between these variables (FQoL, PCS and Perceived Control scores) was analyzed via Pearson's correlation coefficient. A significant correlation was observed between the "Social inclusion and participation" subscale and three dimensions of PCS: Personal growth and maturity ($r = .18$, $p < .01$), Source of happiness and pride ($r = .15$, $p < .05$), Family strength and acceptance ($r = .15$, $p < .05$). Another statistically significant correlation was obtained between "Family accommodation" and Family strength and acceptance ($r = .19$, $p < .01$) and Personal growth and maturity ($r = .15$, $p < .05$). A correlation was also found between "Emotional wellbeing" and Family strength and acceptance ($r = .16$, $p < .05$). Finally, we found a significant correlation between two dimensions of CdVF-E ("Financial wellbeing", "Parents' organization and skills") and Source of happiness and pride ($r = .15$, $p < .05$) ($r = .15$, $p < .05$) respectively.

Therefore, families who felt that their child had contributed to their greater growth as a person, to make the family stronger and to have more acceptance, obtained higher scores in the area of family accommodation. Coupled with the fact that they considered their child brings them happiness, they showed more satisfaction in terms of community participation and social inclusion. These feelings of being stronger as a family and greater acceptance of life events are also related to greater emotional well-being. Finally, considering the child as a source of family happiness is related to greater satisfaction with parental abilities and economic well-being. However, the effect sizes for all statistically significant correlations found can be considered small ($.15 \leq r \leq .19$) (Dunst and Hamby, 2012). No statistically significant relationships were found between other FQoL subscales and PCS dimensions and perceived control.

In relation to our second objective, namely, to predict FQoL scores, a bivariate analysis was conducted. The relationship between monthly family income and FQoL total score was examined via Spearman's correlation coefficient. Results showed a statistically significant positive correlation between them ($r = .146$, $p < .05$): that is, the higher the family income, the better the FQoL. Furthermore, the difference in mean FQoL scores between the families that received personal help to care for their child with ID ($M = 215.27$; $SD = 26.14$) and those that did not ($M = 207.19$; $SD = 28.71$) was also statistically significant ($t(245) = -2.17$; $p < .05$). This indicates that receiving formal or informal support from a relative to care for their child contributes to promote the FQoL. The other family characteristics (parents' age, gender, employment status) and children's characteristics (age, gender, ID level, service that attended to the child, and parental satisfaction with the service) showed no effect on the quality of life of families with children with ID ($p > .05$).

PCS total scores, together with the demographic variables whose effect was found to be statistically significant in the previous bivariate analyses, were included in a multiple linear regression model to predict FQoL scores (see Table 3). Two of the three potential predictors (PCS total score, family income, and support received) were selected by backward stepwise criteria for inclusion in the model. Results indicate that FQoL scores could be predicted by a linear combination of PCS total scores and monthly family income. Therefore, having more positive perceptions and greater economic capacity may predict higher levels of FQoL. In any case, the regression model accounted for only 6.9 % of the variance of FQoL scores (adjusted $r^2 = .069$).

Table 3. Linear regression model of FQoL scores obtained by families (n = 251)

	FQoL overall score				
	B	**SE**	***ß***	***t***	**95 % CI**
Model 1					
Constant	147.56	14.75			
PCS total score	.51	.14	.23	3.49**	.22-.80
Support received	2.90	2.62	.08	1.11	-2.25-8.06
Family income	4.13	1.53	.19	2.69**	1.10-7.15
Model 2					
Constant	150.58	14.59			
PCS total score	.50	.15	.22	3.45**	.22-.80
Family income	4.72	1.44	.21	3.28**	1.88-7.55

** $p< .01$.

4. Discussion

Our results confirm our initial hypotheses that there is a relationship between positive perceptions and FQoL levels. The higher the levels of parental positive perceptions, the greater their FQoL is (Bayat, 2007; Kim *et al.*, 2020). These outcomes suggest that the presence of positive perceptions in a family with a child with ID could improve the family's emotional well-being. This sense of well-being is a function of family members' capacity to overcome challenges and feel agentive in affecting their life conditions. Positive perceptions may, for instance, lead to a feeling of calmness, stress reduction and higher personal and family satisfaction (Fox *et al.*, 2002). Therefore, parents who can perceive the positive aspects of having a child with ID may find their efforts to raise and educate their child worthwhile. They will be motivated to keep supporting their child's development by offering them learning opportunities and they will feel that this process brings them satisfaction as individuals and as a family. This aspect also appears relevant in a previous research (Ferrer *et al.*, 2016), among a population with a wider age range, including adolescents and adults with ID.

Thus, our study emphasizes the need to promote these positive experiences of parenting to preserve the psychological well-being of families. As found in earlier literature (Lloyd and Hastings, 2008), positive perceptions would additionally promote family accommodation, that is, better coping with the experience of having a child with ID, associated with superior adaptation outcomes such as better mental health (Ekas *et al.*, 2019; Wong *et al.*, 2016). Positive perceptions include the ability as a family to accept the reality and find strategies to manage it, feeling that these challenges allow them to grow and move forward. It is widely known that receiving a diagnosis of delayed development problems, ID, autism spectrum disorder, etc., has a negative effect on most families. Families feel vulnerable and require different strategies to cope with fear and anxiety, to recover after the bad news, to redefine parental expectations and the role of each member within the family system and to seek any kind of formal or informal support network (Chiu *et al.*, 2020).

Moreover, an increase in positive perceptions would lead to a better perception of social inclusion and participation. Feeling happy and proud of your child with ID, with more maturity, and considering that the family has become stronger provides families with greater well-being through their social relationships. Participating in the community and feeling included in society increases informal support, which is essential for parents to have, for example, some time off (Harper *et al.*, 2013).

Contrary to our expectations, perceived control does not seem to influence the FQoL level directly. Other variables, such as stress levels and health, which have not been taken into account in this study, may influence this relationship (DeVellis and DeVellis, 2001; Hill and Rose, 2009). Further research is needed to obtain more conclusive results.

When we evaluated the relation between FQoL, parental perceptions and their demographic variables as the second objective of this study, we found that support received played an important role in the degree of satisfaction with quality of life. Since it is considered important for families to have a quality life and be competent in meeting the specific needs of their child with ID, they need a range of resources which can be formal (professionals, healthcare institutions, professional organizations, etc.) or informal (relatives, friends, neighbors, etc.) (Raina *et al.*, 2005). These needs will endure over time and services must provide ongoing support to persons with ID and their families in order to help them to function in typical life activities (Thompson *et al.*, 2009). Previous research in Spain has shown that these families need support throughout their lives, for example, in order to adapt to the experience of caring for a person with ID (Vilaseca *et al.*, 2017).

Even more relevant is the relationship between FQoL and family income. Household income did not have a moderating effect in some studies (Balcells-Balcells *et al.*, 2011; Cohen *et al.*, 2014; Córdoba *et al.*, 2008). However, in other studies it has been found to be a predictor variable of FQoL, even when combined with parental stress or other variables such as family needs (Davis and Gavidia-Payne, 2009; Giné *et al.*, 2015; Hu *et al.*, 2011; Mas *et al.*, 2016; Wang *et al.*, 2004). It must be considered that there are many families in our country in difficult financial circumstances, such as job insecurity or long-term unemployment and therefore low income (INE, 2015). This particularly affects families with a member who has an ID. Resources and support for families with a child with ID are often insufficient to meet their needs, especially financial support, and this situation has worsened in recent years. In fact, in the study by Vilaseca *et al.* (2017), it was reflected that a large part of the sample surveyed considered that the support they received was wholly insufficient to meet their needs, especially financial support. In addition, economic problems are often compounded by the cost of medical or psychological care for the child with ID (Caples and Sweeney, 2011).

Consequently, the results of the current study provide evidence of the importance of promoting family strengths and positive abilities in families with children with ID. It was shown that efforts should continue to involve families in evaluation and intervention processes to achieve better outcomes for children with ID and their families. These results are in accordance with other studies (Brown *et al.*, 2003; Giné *et al.*, 2013; Trivette *et al.*, 2010), showing that a greater FQoL and receiving the right support generate parental feelings of self-efficacy, which are directly related with more positive interactions between parents and their child.

This study has several limitations that should be taken into consideration. First, as this study uses a cross-sectional design, the suggested predictive relations are in fact estimations. In future studies, research should include other variables such as high stress and anxiety levels, family functioning, care burden, and parents' relationship status, which may cause collateral effects that have not been evaluated in the current study. Besides, it would be interesting to complement this research by suggesting future longitudinal studies that assess whether the relations between positive perceptions, perceived control and FQoL change throughout the child's and the family's development.

Finally, it is important to consider the practical implications of this study. It has been shown that working with families of children with ID from a positive perspective and taking advantage of existing family strengths promotes FQoL (Dunst *et al.*, 2019; Dunst and Trivette, 2009; Espe-Sherwindt, 2008). Such strengths may be parents' positive perceptions of their child with ID. It has been proved that these positive perceptions can help the family to adjust to the experience of raising and educating their child with ID. These families need more guidance and help, given the many difficulties their children experience (Kyzar *et al.*, 2012). Therefore, if professionals can incorporate this positive perspective, they will not only focus on the child's condition but also on promoting communication with parents to identify positive perceptions of their child and, consequently, FQoL will increase.

Lastly, our results may be useful as guidelines for professionals of intervention centers. It is more common to focus work plans with families and children on reducing discomfort and working on weaknesses than on fostering insights that bring greater empowerment. Therefore, new intervention strategies for families of children with ID could be developed based on positive perceptions and perceived control. This could help to promote FQoL.

5. Conclusions

This study has three main conclusions. The first is that the presence of positive perceptions in families with children with ID is significantly related to the expression of higher levels of FQoL. The sensation that the child contributes positively to personal and family functioning and well-being fosters greater satisfaction with the FQoL.

Second, other variables such as economic difficulties, job insecurity and even lack of assistance may negatively affect levels of satisfaction with FQoL in families who already have a greater need for support. This conclusion strengthens the idea that governments should provide them with more aid (subsidies, discounts, bonuses, social and care support, etc.) in order to compensate for these difficulties. As reflected in the International Convention on the Rights of Persons with Disabilities (United Nations, 2006), persons with disabilities and their families still suffer exclusion and often have serious difficulties in accessing basic social goods. Public policies and legislation should prioritize actions that uphold their human rights.

Finally, it is essential to incorporate family empowerment in work plans with families and their children. This will enhance the well-being of the caregivers and increase their capacity to respond to the needs of their child with ID. To achieve this aim, governments must adopt policies that provide professionals with guidelines and spaces to create partnerships with the families.

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