

Satisfaction with early attention services and the perception of disability among parents of Down's syndrome children: a pilot study in Spain

Soddisfazione per i servizi di "Presa in Carico" precoce e la percezione della disabilità tra i genitori di bambini affetti da sindrome di Down: uno studio pilota in Spagna

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Family dynamics may be affected if the parents of a child with Down's syndrome are not satisfied with their relations with the early attention service professionals who attend them, or if they have negative view of the disability. The aim of this article is to assess the level of satisfaction and the parents' perceptions (positive feelings, social comparisons and causal attributions) about the disability. To this end, we have adapted the *Beach Center Family-Professional Partnership Scale* and some items from the *Kansas Inventory of Parental Perceptions (KIPP)* to our milieu. The questionnaire thus designed was completed by 32 mothers and fathers of 0 to 3-year-old children who belong to a Spanish organization, the *Association Down of Navarra*. The results show that the parents feel satisfied or very satisfied with their relations with the professionals and have positive perceptions of the disability. The development of collaborative relations between the professionals and the parents and the reassessment of the positive aspects of the disability will also allow for a more effective response to the specific needs and preferences of the family as a whole.

Key words: Down's syndrome, family early attention satisfaction, positive perception, questionnaire

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Le dinamiche familiari possono cambiare se i genitori di un bambino affetto da sindrome di Down non sono soddisfatti della loro relazione con i professionisti che si prendono cura di loro o se hanno una visione negativa della disabilità. Lo scopo di questo articolo è quello di valutare il livello di soddisfazione e la percezione dei genitori sulla disabilità. A tal fine, abbiamo adattato la Beach Center Family-Professional Partnership Scale insieme a alcuni elementi della Kansas Inventory of Parental Perceptions (KIPP) al nostro territorio. Il questionario così concepito è stato completato da 32 madri e padri di bambini dai 0 ai 3 anni appartenenti all'Associazione Down di Navarra (Spagna). I risultati mostrano che i genitori si sentono soddisfatti o molto soddisfatti delle loro relazioni con i professionisti e hanno una percezione positiva della disabilità. Lo sviluppo dei rapporti di collaborazione tra professionisti e genitori e la rivalutazione degli aspetti positivi della disabilità consentirà anche di fornire una risposta complessivamente più efficace alle specifiche esigenze e preferenze della famiglia.

Parole chiave: *Sindrome di Down, soddisfazione della famiglia, percezione positiva, questionario*

Introduction

The presence of a child with Down's syndrome causes certain economic, physical and emotional problems. The day-to-day challenges involved in these burdens may cause greater vulnerability and fragility in the parents (e.g. fatigue, drowsiness, health problems, etc.) (Burke, 2004, 2010; Hastings, Kovshoff et al., 2005; Peralta and Arellano, 2010). Moreover, the additional demands associated with their child's disability may lead them, early on, to require professional services or backing in order to bear the daily routines, to accept their roles and to create a safe environment where the Down's syndrome child will achieve better levels of development and learning (Russell, 2003).

If the parents are satisfied with their interaction with the professional helpers, or feel that they have been properly attended, other aspects which sometimes alter the dynamics of the family such as stress, depression, a feeling of inadequacy or difficulty in decision-making, may be minimized or reduced (Hastings, Beck et al., 2005; Reddon et al., 1992). In addition, if the parents truly and positively accept their child's disability and see themselves as capable of coping with the demands which derive from it, they are better prepared to successfully deal with this experience, and may even be strengthened by it, that is to say, they become more resilient (Bourke-Taylor et al., 2010; Hastings and Taunt, 2002; Behr et al., 1992; Peralta and Arellano, 2010).

Thus, as has been shown by some research (Summers et al., 2005), the degree of parental satisfaction with the early care and attention services affects the quality of family life and also the achievements of the disabled child. Moreover, when the parents develop a more positive perspective and higher aims for their child's advancement, their behavior will, in all probability, actively promote the child's learning process.

Traditionally, the theoretical and empirical work carried out in the area of intellectual disability has paid little attention to the positive feelings that the parents also have on the disability of their child and the positive impact the child may have on the family in general (Durà-Vilà et al., 2010; Hastings et al., 2002). For this reason, an understanding of how the parents see themselves and the disability of their child is a key factor for understanding their behavior and finding alternatives to help them to make use of better resources and strategies for coping.

In this regard, nowadays intervention approaches centering merely on the disabled person have been abandoned, and proposals that recognize the unique needs of each family have been adopted in order to create a collective well-being and the well-being of each and every member of the family (Brown et al., 2010; Scelles et al., 2012; Sheridan and Burt, 2009). Both the Down's syndrome child and his/her family become the protagonists of the process of intervention. The effectiveness of this process depends, to a great extent, on the collaborative interaction of the professionals and the family (Blue-Banning et al., 2004; Dempsey and Keen, 2008; Dunst et al., 2007; Nelson et al., 2004).

Family-professional partnerships are mutually supportive interactions between families and professionals, focused on meeting the needs of children and families, and characterized by a sense of competence, commitment, equality, positive communication, respect, and trust (Blue-Banning et al., 2004; Summers, Hoffman et al., 2005). The seven principles that characterize these relations are: open communication, professional competence, respect, commitment, equality, the advocacy of rights and trust (Turnbull et al., 2006).

The professionals collaborate with families when they:

- have a respectful relation with the families;
- use their qualities as a starting-point;
- help them to identify and understand their needs;
- assist them in prioritizing their aims, preferences and tasks;
- encourage them and support them in decision-making;
- give them responsibilities; improve the family's control over their lives and so promote their self-determination (Blue-Banning et al., 2004; Friend and Cook, 2010).

In this way, the families, with the proper support of the professionals, can learn what they do not know and develop strategies and skills to assist them in their tasks, in future problems and in their needs. As Dunst et al. (1994) say, it is not just an issue of whether the family's problems are solved or not; above all the manner in which they are satisfied will, in all probability, have *empowering* consequences (Graves and Shelton, 2007). Therefore, the first step is to see how the families assess their relations with the early attention professionals. The next step will be to improve their competences and their control over the support they receive.

The aims of this work are, on the one hand, to assess the level of satisfaction of the parents of Down's syndrome children with the relations of the professionals with their children and with the family as a whole. To do so, we have adapted the *Beach Center Family-Professional Partnership Scale* (Summers et al., 2005a) to our milieu. On the other hand, taking as a point of reference the *Kansas Inventory of Parental Perceptions, KIPP* (Behr et al., 1992), we analyze the perception of the disability of the parents in this study. The assessment of the parents' satisfaction with the services and their perception of the disability will probably help to better understand how well they are prepared to deal positively with their children's special needs and to gauge how well the services available are suitable for these needs and those of the whole family. We consider that obtaining these data and their analysis as the foundations on which to base the empowerment of the families.

Material and method

This pilot study aims to assess the satisfaction of the parents belonging to the *Association Down of Navarra*¹ with their

¹ A nonprofit organization (NPO) working since 1990 for the benefit of people with Down's syndrome and their families.

relations with the professionals who attend their children, and to assess their perceptions of the disability. One of the activities carried out by this association, to which we have had access, is the dynamics of the Reception Groups for Parents of 0 to 3-year-old Children with Down's syndrome. In this way we have gathered the data for this study.

The parents were invited to take part in this study by means of the information given to them by the association psychologist in the Reception Groups. After their informed consent, they filled in a self-report questionnaire with their sociodemographic data, the child's demographic variables, the level of satisfaction with the chosen professional and some aspects of their positive perceptions of the Down's syndrome child.

Description of the sample group

The selection of the sample was determined by the availability of the association to collaborate with this pilot study. Therefore this is an *incidental sample*, and so the results of this study cannot be applied to the reference population in general.

The criteria for inclusion were:

1. To be the parents of one child (or more) between the ages of zero and three years old with Down's syndrome
2. To belong to the *Association Down of Navarra*

3. To attend the Reception Groups
4. The sociodemographic data, which describe the parents with whom we have worked, are shown in Table I, which contains a summary of the information expressed in figures and percentages.

As can be seen in Table I, we have access to 32 parents from 20 different families, most of whom were married and form part of a household with 1 or 2 children, work outside the home and are university graduates. Moreover, most of the children with Down's syndrome are girls of between 4 months and 3 years of age.

An interesting point is the high number of fathers in this group (41%). In studies on family participation in assistance groups, the presence of mothers is more common; in this case there is a greater balance. Of the 20 families invited, in 12 both the mother and the father attend the sessions. We can ascribe this fact to such reasons as greater marital cohesion in coping with the disability, more parental involvement in the child's education, a greater need to be linked to the early attention services, or the fact that they already belong to a parents association. Even so, we must state that when only one of the parents attend, there are more mothers (n= 7) than fathers (n= 1).

Table I. Sociodemographic data of participants.

<i>Information of parents:</i>	<i>n= 32</i>	<i>%</i>	<i>Information of parents:</i>	<i>n= 32</i>	<i>%</i>
<i>Gender of Parents</i>					
Male	13	40,6%			
Female	19	59,4%			
<i>Age of Parents</i>					
32-39 years	18	56,3%			
40-47 years	14	43,7%			
<i>Marital status</i>			<i>Job dedication</i>		
Married	27	84,4%	Full time	17	53,1%
Divorced	2	6,3%	Half time	8	25%
Single	3	9,4%	No dedication	7	21,9%
<i>Number of children</i>			<i>Academic degree of parents</i>		
1	12	37,5%	Basic education	3	9,4%
2	14	43,8%	Trade school	5	15,6%
3	5	15,6%	High school	3	9,4%
4	1	3,1%	University degree	21	65,6%
<i>Information of children</i>					
<i>Gender of child with DS</i>					
Male	7	35%			
Female	13	65%			
<i>Age of child with DS</i>					
4-11 months	5	25%	1°	9	45%
12-29 months	7	35%	2°	7	35%
30-36 months	8	40%	3°	3	15%
			4°	1	5%

Tool

One of the tools used in this study is the Beach Center Family-Professional Partnership Scale developed by Summers, Hoffman, Marquis, Turnbull, Poston & Nelson (Summers et al., 2005b) at the Beach Center on Disability of the University of Kansas.

The above authors, on the basis of a qualitative study focusing on families with and without disabled children, designed a total of 60 items in order to assess the communication, commitment, respect, honesty, equality and skills of the service professionals. In the end, they defined 18 items distributed into two sub-scales: 1) *Child-Focused Relationships*, which analyzes the parent's perceptions of the quality of the relations of the professionals with their children; and 2) *Family-Focused Relationships*, with items that give understanding of the perceptions of the parents on the quality of the professionals' relations with the family. The two sub-scales permit assessment of the *importance* of these relations and *satisfaction* with them.

The psychometric analysis revealed that the scale has sufficient internal consistence both as a whole (Cronbach's alpha: .96 on satisfaction and .93 for importance), and for each of the sub-scales: *Child-Focused Relationships* (Cronbach's alpha: .94 on satisfaction and .90 on importance) and *Family-Focused Relationships* (Cronbach's alpha: .92 on satisfaction and .88 on importance) (Summers et al., 2005a).

The original scale has been translated, in parallel by each of the authors, and adapted to the Spanish context. It allows assessment of the degree of satisfaction of the participant families regarding their inter-action with the professionals and regarding the work they carry out with the families (this study has not analyzed the importance the families give to these relations). The specifically designed tool includes two more items together with item 18 from the *Beach Center Family-Professional Partnership Scale*: item 12 ("Do you feel better after speaking with him/her? Does s/he cheer you up, understand you?) and item 20 ("Is s/he interested in your frame of mind?"). In this way, it includes emotional aspects which, we feel, were not sufficiently well represented in the original scale.

To fill in the questionnaire, the parent (mother or father) must first select one of the professionals who has worked with their child in the previous six months and depending on that choice had to respond to the questions presented using a Likert-type 5-point scale (from 1= Very dissatisfied, to 5= Very satisfied).

In our analysis, the psychometric analysis reveals that the satisfaction scale has enough internal consistence (Cronbach's alpha: .90) when only the 18 items common to the original scale are taken into account. We also find good reliability when we consider the two satisfaction sub-scales (Cronbach's alpha: .88 for the relations focusing on the child and .87 for those focusing on the family). Thus, we have found ratings which are similar to those obtained in the original study. When we include the 20 items used in this study (items 12 and 20 are added to the original 20), Cronbach's alpha is .91, so the internal consistency on satisfaction is still good.

On the other hand, some items from the *Kansas Inventory*

of *Parental Perceptions KIPP* (Behr et al., 1992) on the positive perceptions of parents have been used.

The KIPP was designed to investigate parental perceptions for coping with the challenges posed by caring for their special needs children. It is made up of 97 items divided into 4 separate sections: 1) *Positive Contributions* (50 items): the person with disability is seen by the parents as a source of happiness and satisfaction (e.g. thanks to the child, the parent has learned to be more patient, the parents have a broader social network, the mother/father has a different perspective on life); 2) *Social Comparisons* (18 items): comparing one's own family with others that are similar or different; 3) *Causal Attributions* (15 items): blaming the child's disability on a particular cause or reason; 4) *Mastery/Control* (14 items): personal control of the situation or of influencing the achievements of child with disability. The KIPP sub-scales derive empirically from the relative dimensions of the positive perceptions of the families of children with Down's syndrome and show appropriate psychometric perceptions, with satisfactory internal consistency coefficients (Cronbach's alpha coefficients in the range from .56 a .87) (Behr et al., 1992).

The 12 items selected have allowed us, by means of a Likert-type 5-point scale (from 1= Strongly disagree, to 5= Strongly agree), to assess some aspects covered in the first three sections of the KIPP: *Positive Contributions*, *Social Comparisons* and *Causal Attributions*. In this way, we have gathered a certain amount of information on the positive contributions towards the Down's syndrome child, together with the possible positive impact on the parents and on the members of the family as a whole (the disabled child as a source of personal growth and maturity).

It follows from the psychometric analysis that the ratings on perception have appropriate internal consistency (Cronbach's alpha: .73). This value is very similar to that obtained by the authors of the original questionnaire (Behr et al., 1992). Certainly our study only used 12 of the 83 items which are analyzed in the KIPP: positive contributions, comparisons with other families or the causes of the disability, for which reason the comparisons are quite speculative.

The research tool used in our work was finally made up of 32 items, 20 of which aimed at assessing the degree of parental satisfaction with the service professionals with whom they related. The remaining 12 allow us to approach the type of perceptions felt by the parents on their children's disability and on the additional challenges deriving from it. A final section in the survey gathers demographic information on the parents and their families, underlining some aspects in relation to the child with Down's syndrome (age, sex and position among siblings).

Statistical analysis

The data, tabulated on an Excel spreadsheet, were analyzed using the statistical package SPSS. Global descriptive analysis was performed: frequencies, means, standard deviation and percentages and reliability (internal consistency coefficient: Cronbach's alpha).

Results and discussion

The results of this pilot study, which is eminently descriptive and exploratory, are now described. Thus, we follow the structure of the questionnaire used as the survey tool. The first part measures the satisfaction the parents feel with the professionals, and the second, their perception of their child's disability.

As has already been stated, to respond to the items on satisfaction, the parents first had to choose the professional to whom they wished to refer. In this case, it was very clear that the most frequently chosen professional was the psychomotor skills specialist or the physiotherapist (53); far fewer (15) choose the paediatrician (see Table II).

Table II. Choice of the professional.

Child's service provider:	n= 32	%
Physical therapist	17	53,1%
Doctor/ Nurse/ Paediatrician	6	18,7%
Special education teacher	5	15,6%
Psychologist	2	6,3%
Speech therapist	1	3,1%
Teacher	1	3,1%
Social worker	0	0%

This datum draws attention to several issues: given the age of the Down's syndrome children (an average of 21

months and 15 days), the most frequently provided services for these parents are physical therapist; thus, for our sample, it would appear that it is with these professionals that they have spent most time and have a better relationship. On the other hand, most of these children do not attend school, so the parents have not yet had any contact with the other professionals they will later meet (e.g. learning support teachers, social workers); or perhaps these families do not yet need some services which they will later find indispensable (e.g. transition planning).

Parental satisfaction with the professionals

As can be seen in the data in Table III, the results of the study indicate that the parents feel satisfied (average 4 points) with the relationship with their previously selected professional. This tendency to give high values of satisfaction to the early education services is common in the research (Bailey et al., 2003; Johnson et al., 2002; McNaughton, 1994; McWilliam et al., 1995; Peralta et al., 2011; Summers et al., 2007). In addition, these results point in the same direction as those described by the authors of the original scale: thus, most of the parents' responses are between 4 and 5, which seem to indicate that they see their relations with the professionals as satisfactory or very satisfactory.

When we compare the interactions focusing on the child with those focusing on the family, corresponding to the two sub-scales, our study does not show significant differences in

Table III. Satisfaction with the professionals.

	0	1	2	3	4	5
ITEMS:	No answer	Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
1: Helps you...	3,1%	0%	9,4%	15,6%	37,5%	34,4%
2: Has the skills...	3,1%	0%	3,1%	21,9%	31,3%	40,6%
3: Provides services...	9,4%	0%	6,3%	28,1%	28,1%	28,1%
4: Speaks up for your child...	12,5%	0%	6,3%	18,8%	31,3%	31,3%
5: Lets you know about the good things...	0%	0%	3,1%	18,8%	31,3%	46,9%
6: Is available ...	0%	0%	9,4%	31,3%	31,3%	28,1%
7: Treats... with dignity	3,1%	0%	6,3%	6,3%	12,5%	71,9%
8: Builds on your child's strengths	9,4%	0%	3,1%	15,6%	31,3%	40,6%
9: Values your opinion...	6,3%	0%	6,3%	18,8%	21,9%	46,9%
10: Is honest...	3,1%	3,1%	9,4%	21,9%	34,4%	28,1%
11: Keeps your child safe...	9,4%	0%	3,1%	9,4%	31,3%	46,9%
12: Makes you feel better...	3,1%	0%	0%	18,8%	28,1%	50%
13: Uses words that you understand	0%	0%	3,1%	9,4%	28,1%	59,4%
14: ...privacy	3,1%	0%	3,1%	25%	34,4%	34,4%
15: Shows respect...	6,3%	0%	0%	15,6%	43,8%	34,4%
16: Listens...	6,3%	0%	6,3%	6,3%	46,9%	34,4%
17: Is a person... depend on and trust...	0%	0%	0%	21,9%	37,5%	40,6%
18: Pays attention...	0%	0%	0%	15,6%	34,4%	50%
19: Is friendly...	0%	0%	0%	12,5%	21,9%	65,6%
20: Shows interest in your well-being...	3,1%	0%	9,4%	15,6%	43,8%	28,1%

the punctuations on satisfaction. Similarly, nor do we find differences in the punctuations on satisfaction when we take into account the variables of the parents' sex or the sex of the Down's syndrome child.

When we consider a more in-depth analysis of the results for each of the items, we find that the most appreciated issues for the parents (they feel satisfied or very satisfied) are *respect in the dealings with their child* (84%) (Subscale on Relations focusing on the child) and the *use of comprehensible vocabulary* (88%) (Subscale on Relations focusing on the family). These data show the importance they give to the individual and personalized dealings of the professional with the child and with the adults themselves, together with the need the parents have of properly understanding some aspects of their children's development.

However, although we must say that the levels of dissatisfaction are very low, the items with the lowest punctuation (dissatisfied and very dissatisfied) mention aspects that refer to the *perceived honesty* of the chosen professional, *assistance to the parents*, *availability* and *professional concern* about the parents' frame of mind (all of these in 3 parents who are not fully satisfied with these characteristics in the assessed professional). These results have been corroborated in other research works (Summers et al., 2007) which also point out that the professionals find it difficult to respond to the individual needs expressed by the parents, to give them information about the services available and to work with the whole family (Pickering and Busse, 2010). That is to say, they are still in charge while the parents are not yet seen as helpmates (Bamm and Rosenbaum, 2008; Bruder, 2000; Espe-Sherwindt, 2008; Goldfarb et al., 2010; Hardman, et al., 2011).

Evidently, the development of collaborative relations between professionals and parents is not always satisfactory, due to a lack of communication, commitment, skill, honesty or respect (Blue-Banning et al., 2004). But we must agree with the experts that collaborative interaction between pro-

fessionals and family is advisable so as to provide effective services for children with disability and their families.

Nevertheless, as has already been stated, as the children get older, it is very likely that the parents will have to interact with other services and professionals in order to respond to the needs generated over the lifetime of their offspring. In such cases, satisfaction with said interaction may be different and/or less positive than was found in this research.

Perception of the disability

As Table IV shows, the results of the survey show that the parents in our study have a positive and balanced perception of the disability and of the possibly enriching effect it has had, and still has, for them and their families as a life experience.

The parents describe a *greater sensitivity* towards *people with difficulties* (81% agree or totally agree) and they feel more *optimistic* (56%), capable of *accepting things* as they are (56%) and more *patient* (44%). Moreover, and above all, they believe, as do the parents in the study by Greer et al. (2006), that they have *forged very important links with other families* who have had the same life experience (97%). Contact with other parents and with friends and family members is precisely, as suggested by Hastings et al. (2002), the most effective natural support for the development of coping strategies, as long as these people maintain a positive attitude.

However, we find a lower level of agreement and greater disparity in the responses to the questions on social comparisons (item 28: *I feel better when I think about other families who have more problems than my family has*) and on the sense of purpose in life (item 25: *The presence of my child is a reminder that everyone has a purpose in life*). Thus, as a consequence of the children's disability, comparisons with other families or clarifying the purpose of life are aspects the parents see in dissimilar ways.

On the other hand, as was to be expected in the context of application of the survey, we find parents who believe the

Table IV. *Perception of the disability.*

	0	1	2	3	4	5
ITEMS:	No response	Strongly Disagree	Disagree	Neither	Agree	Strongly Agree
21: ... <i>patience</i>	0%	3,1%	12,5%	40,6%	28,1%	15,6%
22: ... <i>awareness...</i>	0%	0%	0%	18,8%	37,5%	43,8%
23: ... <i>common ground</i>	0%	0%	3,1%	0%	40,6%	56,3%
24: ... <i>planning ... future</i>	0%	0%	18,8%	40,6%	28,1%	12,5%
25: ... <i>purpose in life</i>	0%	3,1%	18,8%	46,9%	15,6%	15,6%
26: ... <i>take things as they come</i>	0%	6,3%	12,5%	25%	28,1%	28,1%
27: ... <i>grateful...</i>	0%	9,4%	21,9%	21,9%	21,9%	25%
28: <i>I feel... about other families...</i>	3,1%	21,9%	25%	28,1%	9,4%	12,5%
29: ... <i>child's future...</i>	0%	0%	18,8%	25%	37,5%	18,8%
30: ... <i>God's will</i>	6,3%	50%	12,5%	21,9%	3,1%	6,3%
31: ... <i>chance</i>	3,1%	6,3%	12,5%	6,3%	31,3%	40,6%
32: ... <i>something I failed to do</i>	3,1%	78,1%	15,6%	0%	0%	3,1%

disability of their children is due to chance (72%) and do not feel at all responsible or guilty (only one father blames himself)). As in the study by Hastings, Beck et al. (2005), the item referring to religious convictions was hardly ever chosen as applicable. So we can infer that the participating families had clear knowledge on the origin of the syndrome that affects their children.

Thus, although the parents find more positive than negative aspects in their personal experience with their child's disability, we must remember that these families are just beginning to deal with the challenges this disability brings, and that they still have a long way to go and will encounter both valuable contributions and complicated events.

As for the potential differences between mothers and fathers, some research has analyzed whether they see the contributions of their child with disability differently. In the studies by Hastings, Beck et al. (2005) and Hastings, Kovshoff et al. (2005), the mothers mentioned more positive contributions than the fathers. According to the authors, in this way the mothers balance out the negative experiences springing from greater stress in rearing their child, as traditionally mothers spend more time than fathers caring for and interacting with their child. Nevertheless, they also have more opportunities to observe the positive contributions their child offers. In contrast with this research, in our study we did not find significant discrepancies between the perceptions of mothers and fathers. These results may reflect the limitations of this study which will be dealt with in the following section. A broader sample might have returned different results.

In short, despite the fact that families with a Down's syndrome child may suffer more stress, sorrow and other negative emotions than families whose children show more standard development, the results of this study, like those of other research (Greer et al., 2006; Kaufitz et al., 2010; Rolland and Walsh, 2006), show that the parents consider that this life experience may also create positive perceptions. As positive psychology points out, considering these contributions and strengths may have important repercussions, as the quality support offered by professionals may be reflected in an increase of the positive perceptions expressed by the parents.

Limitations of the study

We must be very cautious in interpreting the information obtained, as the limitations of this study are clear and do not permit us to generalize: this was a small, non-random sample; all the parents belong to the same association and have identical group dynamics. On this point, the high levels of satisfaction are probably due to high levels of acquiescence. That is to say, although the confidentiality of this work was guaranteed, the parents may have felt obliged to express great satisfaction, as they had to give their opinions within the context of an association to which they belong, within a reception group, and in the presence of a professional.

Nor must we forget that these are parents who are greatly

involved in the development of their children, people who, in a very short time (less than three years), have decided to join an association and participate in the support groups so as to undertake activities to help them cope with their new family situations. This implies that they are families with great initiative and adaptability, who are also concerned and engaged in attaining knowledge to deal with the situation they face.

On the other hand, given that this is a pilot study, we have chosen to use the tool as a method of screening, in a merely exploratory way. This is why we have only analyzed parental satisfaction regarding their relations with the professionals and have not analyzed the importance they give to each of said aspects (as in the original scale). In addition, only 12 of the original items in the inventory on positive perceptions have been used; the selection of items does not respond to a predetermined criterion, but to our interest in discovering the tendency expressed by the parents on the impact the disability has on their lives.

A broader study, therefore, is necessary (with a more representative sample) in order to analyze both the satisfaction with the services and the importance of these services for the parents. It should focus more specifically on the analysis of positive perceptions and their links with coping (for example, strategies for resolving problems or for detachment from them). Expanding this research with other studies, for example, the application of the full KIPP, would allow for more in-depth analysis of the potential positive impact of the disability on the families. The analysis of this relationship may also be of great significance in supporting the parents of children with Down's syndrome.

Conclusions

This article has presented a descriptive study of the parents of zero to three-year-old children with Down's syndrome in order to recognize some of their perceptions on the disability and their satisfaction with the professionals who attend them. To do so, a tool was designed based on the *Beach Center Family-Professional Partnership Scale* and the *Kansas Inventory of Parental Perceptions-KIPP*, both of which were developed by the Beach Center on Disability of the University of Kansas.

The results indicate that the parents see their relationships with the early attention professionals as satisfactory or very satisfactory. They believe the professionals can systematically attend both the needs of the children and of the families. On this point, the literature underlines the importance of establishing links between parents and experts, particularly at an early stage. Thus the families must be trained to become real collaborators in planning and providing services. As we have seen, positive interaction, active listening, confidence and respect for the families' priorities are frequent in the first few years.

However, it is likely that, as the children grow, the parents will have to interact with other services and professionals in order to respond to the mounting needs of their off-spring. In such cases, the satisfaction shown may well be different and/or less positive than in this survey. Several authors have warned of the problems that professionals have in dealing with the family as a whole when the person with disability is reaching adulthood (Bamm and Rosenbaum, 2008; Pickering and Busse, 2010). Reflection is needed on how to maintain the close and positive links that are frequently found in early attention services over a period of years.

Moreover, the parents have a balanced perception of the disability and the enriching influence it has had or still has as a life experience. Coinciding with the data from other research, the experience of disability may help the parents to develop a stronger, more optimistic and resilient personality. As professionals, we must be aware of these positive perceptions of the parents of children with Down's syndrome. Encouraging the families to focus on the positive points, and not merely on the problems, may be used as a therapeutic technique to improve results and reduce problems such as stress and depression.

As the specialized literature states, awareness or one's own strengths and resources and the creation of collaborative relations with the professionals emerge as the key factors to adapt positively and successfully. Although these seem to be present in the first few years of the child's development, proposals for future works with access to broader and more diverse samples remain pending, particularly with older children.

We believe that the results show how useful tools like these can be in order to have a more in-depth understanding of the way in which parents face up to the obvious challenge of looking after their Down's syndrome children and the quality of their interactions with the professionals. It would be advisable to have properly validated, simple tools for routine use, which, on the basis of the information obtained, could be used to adjust programs and services to the needs of both the children with disability and their families.

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