METAS DE SOCIALIZAÇÃO E ESTRATÉGIAS DE AÇÃO DE PAIS E MÃES DE CRIANÇAS COM SÍNDROME DE DOWN

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Resumo

A presente pesquisa teve como objetivo principal investigar as metas de socialização e estratégias de ação que pais e mães têm para os seus filhos com Síndrome de Down (SD). Participaram 24 mães e 19 pais de crianças com SD, com média de idade de 22 meses, residentes na região de Itajaí, localizada no sul do Brasil. Utilizou-se como instrumentos a Entrevista de Metas de Socialização e um questionário sociodemográfico. Empregou-se a análise temática categorial para o tratamento dos dados da entrevista. As frequências de respostas dos participantes para cada categoria e, também os dados do questionário sociodemográfico foram analisados por meio de testes estatísticos paramétricos e não paramétricos. Os resultados indicaram que os genitores compartilhavam metas de socialização semelhantes: o autoaperfeiçoamento, relacionado à autonomia e independência, foi a meta significativamente mais almejada. A expectativa de que a criança com SD tenha um desenvolvimento típico também foi uma das preocupações dos genitores em relação ao futuro dos filhos. Os genitores se assemelharam quanto às estratégias empregadas: ambos atribuíram principalmente a si a responsabilidade de assegurar que a criança atinja os objetivos almejados. Conclui-se que a mudança na visão da deficiência, o aumento da expectativa de vida da população com SD, a criação de políticas públicas e o fato das crianças estarem inseridas em contextos institucionais pode ter interferido no predomínio de valores dos genitores, relacionados à autonomia e independência dos filhos com SD.

Palavras-chave: Síndrome de Down, Metas de socialização, Crenças parentais.

SOCIALIZATION GOALS AND ACTION STRATEGIES OF PARENTS OF CHILDREN WITH DOWN SYNDROME

Abstract

The present study aimed to investigate socialization goals and strategies that guide parents’ actions towards children with Down Syndrome (DS). In total, 24 mothers and 19 fathers of children with DS participated, with an average age of 22 months and living in the Itajaí region, located in Southern Brazil. Data were gathered from parents’ answers to the Socialization Goals Interview and a socio-demographic questionnaire. A categorical thematic analysis was applied for the treatment of data interview. Parametric and non-parametric statistics were also used to analyze part of the data from both surveys. Results indicated that parents shared similar socialization goals: self-improvement related to autonomy and independence was pointed out as the most desired objective. The expectation that children with DS have a typical development was also one of the parents’ concerns regarding children’s future. Parents had similar opinions about the strategies employed. Mainly, they attributed to themselves the responsibility to ensure that children could achieve the desired goals. It is possible to conclude that the change in the way DS condition is perceived, an increase in life expectancy of people with Down syndrome, the creation of public policies and the fact that children are placed in institutional contexts may have influenced parents’ predominant values about autonomy and independence of children with DS.

Key words: Down syndrome, socialization goals, parental beliefs

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OBJETIVOS DE SOCIALIZACIÓN Y ESTRATEGIAS DE ACCIÓN DE LOS PADRES DE NIÑOS CON SÍNDROME DE DOWN

Resumen

El propósito de este estudio fue el de investigar los objetivos y estrategias de socialización que los padres tienen para sus hijos con síndrome de Down (SD). Participaron 24 madres y 19 padres de niños con síndrome de Down, con una edad promedio de 22 meses y que viven en la región de Itajaí, ubicada en el sur del Brasil. Se realizó una entrevista sobre las metas de socialización y un cuestionario sociodemográfico. Se aplicó el análisis temático categórico para el tratamiento de los datos de la entrevista. Las frecuencias de las respuestas de los participantes a cada categoría y los datos de los cuestionarios sociodemográficos también fueron analizados. Los resultados indicaron que los padres comparten metas similares; ellos desean de manera significativa el autoperfeccionamiento relacionado con la autonomía y la independencia de sus hijos. La expectativa de que los niños con síndrome de Down tengan un desarrollo típico fue también una de las preocupaciones de los padres. Los progenitores emplearon estrategias semejantes: ambos se atribuyeron para sí la responsabilidad de asegurar que el niño logre los objetivos deseados. Se concluye que el cambio en la forma como se percibe la condición de SD, el aumento en la expectativa de vida de las personas con este síndrome, la creación de políticas públicas y el hecho de que los niños sean ubicados en instituciones, pueden haber influenciado los valores predominantes de los padres con respecto a la autonomía e independencia de los niños con síndrome de Down.

Palabras clave: Síndrome de Down, metas de socialización, creencias de los padres.

INTRODUCTION

Parents have beliefs and values about parenting that influence parental behavior. These beliefs are culturally-based and organized into broad categories that interfere and direct parents’ choices, decisions and actions in providing the children’s care. They are called cultural beliefs system of parenting or parental ethnotheories (Keller & Kartner, 2013). Parental ethnotheories can be classified in terms of what caregivers think about: a) child development; b) care practices and c) socialization goals. These aspects relate to the cultural model of parenting prevalent in each social context.

The present study focused on “socialization goals”, understood as behaviors desired by parents for their children when they become adults. As such, they also relate to the parents’ personal values and societal values that influence the desired behavior, according to the cultural context in which they live and, therefore, they can influence educational practices adopted by parents. To reach the expectations for their children’s development, parents create some strategies known as action strategies that may favor the attainment of their socialization goals (Harwood, Schoelmerich, Ventura-Cook, Schulzee Wilson, 1996; Miller & Harwood, 2001).

These strategies can be self-centered, in other words, parents believe children depend on their care for them to meet the desired goals. Strategies may also focus on the context, which means parents believe that in order to reach the developmental expectations for their son/daughter they need other critical factors available in their environment such as the social support network and the school. Finally, strategies can be child-centered. In this case, parents assign more importance to their child’s role in his/her own development to reach the desired behavior in the future.

According to Keller, Borke, Yovsi, Lohaus and Jensen (2005), the investigation of caregivers’ socialization goals can contribute to understanding the parenting cultural model of the target population. The authors have observed that some cultural models may have values more linked to the independence model, while others have stressed the interdependence model. The cultural model of independence refers to the construction of the self as individual and distinctive, valuing his personal goals, needs and rights. On the other hand, in the cultural model of interdependence, there is a self-related prevalence for group members, valuing group goals, social roles, duties and obligations. That cultural model is characterized by the value attached to heteronomy and relationship (Keller et al., 2005).

A third cultural model proposed by Kagitçibasi (2005) and called autonomous-relational encompasses characteristics of both independence and interdependence models. It comprises attributes of autonomy and relationship, in which the self is defined as autonomous in action and relational in interpersonal closeness (Keller & Kartner, 2013).

International studies have shown a prevalence of research whose primary objective is the comparison of socialization goals in different contexts (Citlak et al., 2008; Friedlmeyer, et al., 2008; Keller et al., 2006; Lordelo, Roethle, Mochizuki, 2012; Miller & Harwood, 2001). In these investigations, it was found that socialization goals and cultural model of parenthood are influenced
by the context in which parents live. For example, Brazil is a country with continental dimensions, and there are differences between different regions (Seidl-de-Moura et al., 2008).

A significant research conducted by Seidl-de-Moura et al., (2008), which involved different Brazilian cities, aimed to identify the socialization goals of Brazilian mothers of children with a typical development. A total of 349 mothers living in the South, Southeast, North, Northeast and Center-West of Brazil participated in the study. Results showed that the most valued goals relate to the categories of self-improvement and proper demeanor. The first category (self-improvement) is associated with parents’ desire that their children may have autonomy and independence in the future. On the other hand, the second category was characterized by parents’ expectation that their children could show appropriate behavior in social situations and could have good relationships with people.

Other studies, for example, Bandeira, Seidl-de-Moura and Vieira (2009), Diniz and Solomon (2010), Seidl-de-Moura et al., (2009), Seidl-de-Moura, Carvalho and Vieira (2013) and Vieira et al., (2010) conducted with families of children with typical development, in the Brazilian context, have obtained similar results and have confirmed the autonomous-relational cultural model dominance. Apparently, Brazilian parents have the aspiration that their children reach some independence, but at the same time, they want them to preserve social values and develop skills to establish and maintain positive relationships with others.

It is important to mention that those studies were conducted with parents of normally developed children or children who did not have any disability. It is worth assuming that there would be a difference in the parents’ socialization goals of children with atypical development as a function of the specificities of their disability.

Therefore, precisely, the focus of the present study is to investigate socialization goals among parents of children with atypical development, particularly, children diagnosed with Down Syndrome (DS). How do parents adapt their practices to their children’s needs, and what behaviors are emphasized to reach those goals? The purpose here is to answer those questions and compare differences and similarities in the objectives sought by mothers and fathers. In the context of disability, socialization goals were researched by Freitas and Magellan (2013). The research aimed to investigate how mothers of deaf children established the socialization goals for them. Results showed that the most emphasized goal was social expectation, that is to say, that the child develops values like being honest, hardworking and has religious values. The next most valued goals were appropriate behavior and self-improvement. As for the action’s strategies used to reach the goals, the mothers of these children attributed themselves the greatest responsibility of creating conditions for their children to achieve the desired expectations.

It is possible to assume that the birth of a child with a disability can cause instability in the family due to the rupture of parents’ expectations related to an ideal baby. As a result of this unexpected event and especially of the way parents deal with the situation, interaction difficulties may arise (Brasington, 2007).

Academic reviews performed by Dessen and Pereira-Silva (2000) and Henn, Piccinini and Garcia (2008) pointed out that there is a lack of studies investigating the family context of children with disabilities, especially the research that includes the father’s role in such context (Henn & Sifuentes, 2012). Thus, the child with Down syndrome has a different rhythm of development compared to other children, and most parents are not prepared for that. Consequently, the situation is a potential anxiety-producer and may bring uncertainty in the care parents will provide for their children (Henn et al., 2008). Difficulties in interacting with a child with Down syndrome (DS) can produce limited expectations about her/his development, and consequently, it will influence parenting practices. This study opted for the DS as it is considered one of the most common syndromes. DS, also known as trisomy of 21 chromosome is a genetic disorder that causes changes in physical and mental development (Kozma, 2007).

Based on the literature, it was possible to establish the following hypothesis for this study: 1) Fathers and mothers will report similar socialization goals and strategies since they share the same developmental context. 2) Due to different characteristics in the rhythm of the DS child’s development, it is expected that both mothers and fathers will set similar goals to those in the research of Freitas and Magellan (2013). In other words, parents will mainly favor goals related to social expectations and good behavior, thus reflecting an interdependent cultural model of self. 3) According to the theoretical model of Harwood et al. (1996), the predominance of goals related to social expectations and good behavior reveal a socio-centric or interdependent cultural model of parenthood. 4) As children with Down syndrome require more specific care provided by their parents, it is believed that the strategies centered on parents’ care will be predominant in relation to strategies focused on the context and on the child himself/herself.
METHOD

Participants

The participants of this study were 19 fathers and 24 mothers from families treated by four institutions specialized in the care of children with Down syndrome, in the Itajaí Valley region, Southern Brazil. All of them were biological parents of the children. Some fathers did not participate in the survey because they did not feel comfortable to talk about the development of their son/daughter or they had separated from the child’s mother and/or were living in another city.

The sample inclusion criteria demanded that couples should have a son/daughter, aged between 0 and three years old and diagnosed with Down syndrome (ICD-10: Q90). The age range was established to match one of the critical moments of human development, in which parental investment is essential for the child’s survival. On the other hand, the sample exclusion criterion was the presence of comorbidity of that diagnosis with other mental disorders or syndromes of organic origin.

Instruments

It was possible to use a semi-structured questionnaire developed by Harwood et al., (1996) and adapted to the Brazilian context by Seidl-de-Moura et al., (2008) to access the socialization goals. The instrument consists of two questions: 1) Which qualities do you wish your son/daughter to have as an adult? 2) What do you think it is necessary for him/her to develop these qualities?

The instrument choice was due to its adequacy for the study, and also because it was widely used in research in the area of parental ethnotheories (Banner et al., 2009; Citlak et al., 2008; Diniz & Solomon, 2010; Freitas & Magalhães, 2013; Lordelo et al., 2012; Miller & Harwood, 2001; Seidl-de-Moura et al., 2008; Seidl-de-Moura et al., 2009). Furthermore, the purpose was to test the instrument adequacy in a sample of parents of children with disabilities as Freitas and Magalhães did (2013), but in this occasion including another type of disability: Down syndrome. There was also a sociodemographic questionnaire that consisted of 15 questions on family information such as city of residence, family composition, number of people living in the house, age and education of family members, household income, child’s primary caregiver and features of the house.

Procedure

Step 1: First, the coordinators’ signatures of special education institutions were obtained to formalize the consent between parties, and thus, to allow the researcher access to the target families.

Step 2: The project was submitted to the Ethics Committee in Human Beings of the Universidade Federal de Santa Catarina and received the favorable opinion number 274 379).

Step 3: The researchers returned to specialized institutions and asked for permission to access the children’s registration attending the school that could meet the criteria for inclusion in the survey.

Step 4: After the participants pre-selection, the researchers invited them to participate in the study through personal or telephone contact with fathers and/or mothers, scheduling time and place to meet with them according to their preferences.

Step 5: After explaining the study’s proposal to the participants and obtaining their formal consent, they were asked to sign the Informed and Free Consent Form. Subsequently, it was possible to apply the instruments.

Step 6: The socio-demographic questionnaire was administered and recorded by the researcher. Afterwards, the Interview on Socialization Goals was applied, tape-recorded and fully transcribed later. All participants responded to the Socialization Goals Interview, separately, to prevent the response of one parent to influence the answer given by another one.

Data Analysis and processing

Data analysis was conducted both quantitatively and qualitatively. The qualitative approach was adopted to analyze data from the interview on Socialization Goals. Thus, it was possible to use the content analysis technique by themes, suggested by Bardin (2003). The analysis was performed according to categories previously defined by Harwood et al., (1996) and adapted to the Brazilian context by Seidl-de-Moura et al., (2008). It was decided to maintain the same categories to verify the model’s adequacy to explain the phenomenon of socialization goals in the family with children with disabilities. It is noteworthy that the categories were mutually exclusive, that is to say, none of the descriptions was classified in more than one category. The categories and their definitions are presented as follows;

Self-improvement: concern for the child to become self-confident, independent and to develop his/her talents and abilities as an individual. Self-control: concern for the child to develop the ability to control negative impulses of greed, aggression or self-centeredness. Emotionality: concern as for the child to meet the social expectations of being hardworking, honest and law-abiding. Good behavior: concern that the child behaves well, gets along with others and plays well-
expected roles (good father, good mother, good wife, etc.), especially about the family.

During the analysis, it was possible to realize the need to create another category called “typical development”. This one emerged from the discourse of fathers and mothers because of the particularities of the population with DS, and parents’ desire that their son/daughter could have an ordinary life, similar to people without disabilities. The definition of that category is the following: Concern that children with Down syndrome can have a developmental trajectory similar to children with no disabilities.

Based on the answers to the first question on “Socialization Goals”, they were associated to the prototypical cultural models of parenting (individualistic and socio-centric). Self-improvement and self-control goals belong to the first model (individualistic). On the other hand, socialization goals involving categories such as social expectation, emotionality and good behavior are attributed to the socio-centric model.

The definitions of the dimensions of parenting models are: (a) Individualist: Construction of the self as fundamentally unique and distinct, and (b) Socio-centric: construction of the self as fundamentally linked to other individuals. On the other hand, the responses to the second question were classified regarding possible action strategies: Self-Centered (SC) - parents would be models or would provide them. Centered on the context (CC): provides excellent social opportunities. Centered on the child (CCh): the child is actively involved in the process of development and parents consider the child as an active agent for her/his own development.

Subsequently, a reliability test to assess whether the units of analysis had been inserted into the appropriate categories was carried out. In this case, the researcher was helped by two other scientists who acted as judges. The reliability index (RI) for the first question from the judges was 90% in the group of fathers, and 83% in the panel of mothers. Regarding the second question, both fathers and mothers reached an RI of 73%. According to Fagundes (1999), indices of results above 70% are considered acceptable to indicate agreement.

The answers to all instruments were analyzed with the aid of statistical analysis programs. In addition to descriptive analysis, the t-test was conducted to compare responses between fathers and mothers only when data had normal distribution while non-parametric tests were used in the case of non-normal distribution (Mann-Whitney and Wilcoxon).

RESULTS

First, the socio-demographic data will be presented to characterize the families. Then, results arising from the interview about socialization goals will be shown, mentioning the main objectives emphasized by parents, the cultural model of parenting associated with parental values, and finally, strategies used by parents to reach their children’s development expectations.

Socio-demographic characterization of the participants

Participants’ average age was 34 years (M = 34.05) for parents and 32 years (M = 32.13) for mothers. Most of the couples, 83.3% (n = 20) were married or in stable relationships. Among the surveyed families, in 54.2% (n = 13) of cases, the child with DS was the only offspring of the family. The mother was the principal care provider for the son/daughter. 50% (n = 12) of them did not have any paid work and were dedicated full time to the child. Every father had a paid employment outside the home. Consequently, fathers had a higher income than mothers. However, parents’ education ranged from illiterate to post-graduates, and there was no significant difference between fathers and mothers in terms of schooling.

Children’s ages ranged from four to 42 months (mean = 22.21) and 50% (n = 12) of the sample was female. Regarding the school situation, 33.3% (n = 8) attended regular school and a special education institution while the majority, 66.7% (n = 16), only attended a special education institution.

Socialization goals

In the analysis of the interviews a total of 225 words or descriptive phrases for socialization goals were coded. The average of coded answers per participant was 5.2. Of the total responses, 89 (M = 4.68) were provided by parents and 136 (M = 5.67) by mothers. However, the difference was not statistically significant. Table 1 presents descriptive data for the socialization goals categories.
Table 1.
Frequency, percentage and average of coded responses per category of socialization goals

<table>
<thead>
<tr>
<th>Category</th>
<th>Total responses</th>
<th>%</th>
<th>Fathers Mean (SD)</th>
<th>Total responses</th>
<th>%</th>
<th>Mothers Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-improvement</td>
<td>52</td>
<td>58.43</td>
<td>2.74 (2.26)</td>
<td>80</td>
<td>58.82</td>
<td>3.29 (2.37)</td>
</tr>
<tr>
<td>Self-control</td>
<td>2</td>
<td>2.25</td>
<td>0.11 (0.32)</td>
<td>2</td>
<td>1.47</td>
<td>0.08 (0.41)</td>
</tr>
<tr>
<td>Emotionality</td>
<td>3</td>
<td>3.37</td>
<td>0.16 (0.37)</td>
<td>9</td>
<td>6.62</td>
<td>0.38 (1.06)</td>
</tr>
<tr>
<td>Social expectation</td>
<td>9</td>
<td>10.11</td>
<td>0.47 (1.02)</td>
<td>15</td>
<td>11.03</td>
<td>0.63 (1.06)</td>
</tr>
<tr>
<td>Good behavior</td>
<td>6</td>
<td>6.74</td>
<td>0.32 (1.16)</td>
<td>7</td>
<td>5.15</td>
<td>0.29 (0.86)</td>
</tr>
<tr>
<td>Typical development</td>
<td>17</td>
<td>19.10</td>
<td>0.89 (0.99)</td>
<td>23</td>
<td>16.91</td>
<td>0.96 (1.16)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>89</strong></td>
<td><strong>100%</strong></td>
<td></td>
<td><strong>136</strong></td>
<td><strong>100%</strong></td>
<td></td>
</tr>
</tbody>
</table>

There was a verification of the goal that best characterizes the sample studied. Thus, it was possible to use the nonparametric Wilcoxon test to verify differences between the goals of the same groups. Data analysis revealed, both for the group of fathers and mothers, a significant difference between the average of responses to the self-improvement goal and the averages of other categories (p < 0.05).

This result did not confirm the second hypothesis of the study. It was expected that goals related to social expectations and good behavior should be the most desired ones due to the sample characteristics. The predominance of goals related to self-improvement showed a prevalence of values related to autonomy and independence over other socialization goals desired by parents.

The self-improvement category was the most mentioned in both groups. Examples of answers classified in this category are related to the concern that their son/daughter can be independent, confident, fulfilled, can complete their studies and get their own jobs. One of the mother’s discourses was: “I hope he will study hard and graduate from university” (mother ID1105).

Secondly, fathers and mothers were more concerned that their son/daughter with Down syndrome might have a healthy development, i.e. similar to children without disabilities. This goal can be illustrated in fathers and mothers’ discourse as the following: “To have a normal life and with the same quality like any other person” (ID4111 mother).

Social expectation category was the third most cited by parents. Fathers and mothers seemed to give more emphasis to certain virtues as being honest, hardworking and have religious values. For example: “I want him to be an honest, righteous man, a good citizen” (father ID2201).

Good behavior and performance of social roles were the fourth most desired goal by fathers, with a 6.74% (n = 6). Nevertheless, the group of mothers, 6.62% (n = 9) valued more the emotionality, revealing the desire that the child could be affectionate and also loved by people.

In the fifth category, there was a difference between groups. There was an inversion of goals. Fathers gave, in 3.37% (n = 3) of the responses, greater emphasis on emotionality while mothers appreciated the good behavior, 5.15% (n = 7). The following phrases exemplify some of the participants’ discourse regarding these categories. A father (ID 1112) provided an example of good behavior by saying: “One good quality is to respect others.” The category emotionality can be exemplified by a father’s discourse (ID5110): “She/he [child] reflects this love in other people’s lives.”

Finally, self-control was the least mentioned by parents. This goal is related to parents’ concern about the need for their child to control his/her negative impulses as aggression. Among the few statements provided by participants, the following one can be underlined: “He/she could be a calmer person” (ID2202 mother).

The Mann-Whitney test was used to identify any differences between mothers and fathers about socialization goals and verify the study’s first hypothesis. Results did not show significant differences (p > 0.05) confirming the first hypothesis, i.e., fathers and mothers do not show any differences in socialization goals for their children with Down syndrome for sharing beliefs and values of the same context.
Table 2.
Results of descriptive analysis and t-test related to fathers and mothers’s responses

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Total responses</th>
<th>%</th>
<th>Fathers Mean (SD)</th>
<th>Total responses</th>
<th>%</th>
<th>Mothers Mean (SD)</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individualistic</td>
<td>54</td>
<td>75</td>
<td>2.84 (2.19)</td>
<td>81</td>
<td>72.32</td>
<td>3.38 (2.32)</td>
<td>0.77</td>
</tr>
<tr>
<td>Sociocentric</td>
<td>18</td>
<td>25</td>
<td>0.95 (1.65)</td>
<td>31</td>
<td>27.68</td>
<td>1.29 (1.78)</td>
<td>0.65</td>
</tr>
<tr>
<td>Total</td>
<td>72</td>
<td>100%</td>
<td></td>
<td>112</td>
<td>100%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>t</td>
<td>2.43*</td>
<td></td>
<td></td>
<td>3.19**</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: *p<0.05; **p<0.01

To verify the third hypothesis of this study, an analysis of the goals regarding individualistic and socio-centric dimensions was carried out. Table 2 shows that fathers and mothers present significant differences in their answers. Both caregivers value more the goals related to individualistic dimension compared with the sociocentric dimension. This result did not confirm the third hypothesis of the study, and it is directly associated with the second hypothesis. The predominance of self-improvement goals possibly generated a trend toward a cultural parenting model oriented to individualism. The following is a description of the parent’s action strategies so that their children reach their developmental goals.

Action strategies

In total, 170 responses were identified about action strategies. Based on Table 3, it was possible to register that mothers showed a greater number of responses than fathers. The Mann-Whitney test results identified that there were no significant differences between the two groups regarding total strategies.

Table 3.
Frequency, percentage, mean and standard deviation for each category

<table>
<thead>
<tr>
<th>Category</th>
<th>Total responses</th>
<th>%</th>
<th>Fathers Mean (SD)</th>
<th>Total responses</th>
<th>%</th>
<th>Mothers Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Centered on context</td>
<td>17</td>
<td>23.94</td>
<td>0.89 (1.10)</td>
<td>37</td>
<td>37.37</td>
<td>1.54 (1.67)</td>
</tr>
<tr>
<td>Centered on child</td>
<td>7</td>
<td>9.86</td>
<td>0.37 (0.76)</td>
<td>3</td>
<td>3.03</td>
<td>0.13 (0.45)</td>
</tr>
<tr>
<td>Self-centered</td>
<td>47</td>
<td>66.20</td>
<td>2.47 (1.81)</td>
<td>59</td>
<td>59.60</td>
<td>2.46 (1.35)</td>
</tr>
<tr>
<td>Total</td>
<td>71</td>
<td>100%</td>
<td></td>
<td>99</td>
<td>100%</td>
<td></td>
</tr>
</tbody>
</table>

Table 3 shows that the most valued strategy for fathers and mothers was the self-centered one, followed by the category centered on context, and finally, the strategy focused on the child. However, no significance levels were found through the Mann-Whitney test to corroborate differences in results between groups of fathers and mothers in all categories of action strategies. Although strategies centered on themselves were the most mentioned by parents, they do not present statistically significant differences to confirm the fourth hypothesis of the study. It was expected that these strategies would be predominant in relation to strategies focused on the context and on the child himself.

DISCUSSION

Results obtained in this research indicate that fathers and mothers desire values such as autonomy and independence to their children with Down syndrome. In most studies conducted in populations with typical development and following the same methodology of this investigation, it was possible to find that it was also the desired goal by parents (Banner et al., 2009; Diniz & Solomon, 2010; Seidl-de-Moura et al., 2008). Results are consistent with findings in papers that investigated values and expectations of families of children with Down syndrome; however, they used different instruments and theoretical backgrounds as
well as a qualitative approach (Pereira-Silva & Dessen, 2007). Researchers also found that parents want qualities linked to attributes that define the self-improvement goal, for example, they want their children to be independent, autonomous, to study and have a profession.

These results are different from the second hypothesis of this study that expected to find goals related to an interdependent cultural model, according to Freitas and Magalhães (2013). In the research with mothers of hearing impaired children, there was a predominance of goals on social expectations and good behavior, suggesting a cultural model of parenting focused on interdependence in the context of disability. Apparently, the degree of commitment that language implies for child development makes mothers hard to believe that their hearing impaired children can reach a certain level of independence. Furthermore, in the context of families of children’s with DS, Henn et al., (2008) point out that specificities in developmental rhythms of these children may generate uncertainty in parents about performing parenting. Thus, it was not expected that parents of children with Down syndrome aspire, so significantly, the self-improvement goals.

The second biggest parents’ concern of this research is to wish that their children have a typical development, that is to say, similar to children without disabilities. Other studies also found similar results to the findings of this research, showing a trend of parents estimating that their son/daughter may have a development considered as normal (Pelchat, Lefebore & Perreault, 2003; Singh & Aiello, 2009). The social expectation goal was the third most frequently cited by both parents. Qualities such as being honest, hardworking and respecting the law were values considered as important by parents who participated in the survey. Also, studies conducted with parents of normally developing children confirm the importance of social expectation goals (Banner et al., 2009; Diniz & Solomon, 2010; Seidl-de-Moura et al., 2008). In the field of disability, it is possible to mention Freitas and Magalhães study (2013), in which social expectations were the most desired goals of mothers whose children had a hearing impairment.

In general, fathers and mothers of children with DS assigned more importance to the goals of autonomy and independence of a son/daughter whose development is close to the expected by children without disabilities. Consequently, the individualistic cultural model predominated over the sociocentric one for the group of fathers and mothers. Results with parents who have children with Down syndrome are consistent only with the Brazilian studies of Seidl-de-Moura et al., (2008, 2009) carried out with Rio de Janeiro mothers of children without disabilities, in which there is a predominance of the individualistic model about the one designed as sociocentric. Changes in the Brazilian socioeconomic scenario may have favored the emergence of a tendency among parents to incline to the socialization goals that emphasize the development of characteristics related to autonomy, including the desire for a higher level of education for their children. These characteristics are associated to the significance of individual success in societies with high levels of industrialization and education (Lordelo et al., 2012).

These results can also be attributed to society’s changing vision on disability in the last century. These changes contributed to the development of public policies aimed at promoting development and ensure the rights of that population. Therefore, these people began to gain visibility and access to services because they were no longer seen as incapable beings. More specifically, and regarding people with Down syndrome, the advancement of knowledge about the syndrome increased their expectancy and quality of life (Portes, Vieira, Crepaldi, More & Motta, 2013).

Parents’ preferences for values about autonomy and independence can also be explained by the fact that, ultimately, individuals with Down syndrome show an increase in academic standards and achievements throughout their lives (Hodapp, 2007). Professionals’ participation in guiding families of children with disabilities, specifically those affected by DS, is considered as an important factor to help parents in the reorganization of their expectations, and also, to develop a more positive outlook on the son/daughter with Down syndrome.

Thus, reflections on cultural and political aspects contribute to the understanding of expectations outlined by parents for their children with Down syndrome. They become a socioeconomic influence on family values, on the change of perception about disability, on public policy creation about inclusion, knowledge dissemination on DS, and increased participation of specialized and professional institutions in caring for children with Down syndrome. The factors’ incremental impact seems to have an influence over parental values, and thus, they reflect the cultural model of parenting that best suits expectations, parental and social values.

Socialization strategies used by parents to reach goals fixed for their children’s development also provide important indicators in child rearing practices. In this paper, the most valuable strategy for fathers and mothers was the one focused on them, followed by the approach centered on the context and, finally, the one centered on the child. Therefore, it is clear that parents believe they are primarily responsible for assisting the child in reaching certain
objectives during his/her development, by teaching and providing good examples.

Context-oriented strategies were also reported by parents, especially mothers. These data show the importance of social support network such as the family, and mainly, the institutions specializing in these children’s care regarding stimulation, which is essential for any child and, most specifically, for that population. Also, social support networks provide information and guidance for families. Finally, parents assign less importance to the strategies focused on the child’s abilities. That happens because even though parents expect their child to become an independent individual as an adult, they do not seem to believe that their son/daughter with Down syndrome can be a protagonist of his development. These children will possibly rely on their parents’ help and support network because of their limitations.

In the research with families of hearing impaired children (Freitas & Magalhães, 2013) and with normally developed children (Banner et al., 2009; Diniz & Solomon, 2010; Mills et al., 2007), results indicated that parents also believe they should serve as behavioral models and guide their children to reach the goals estimated for their development. Once again, it is clear that the children’s parents with and without disabilities share the same parental values regardless of specifics, in the course of these populations’ development. In conclusion, this research seems to suggest that parents, at the early developmental period, expect their children to reach autonomy and independence over time. This does not seem to be necessarily linked to the child’s characteristics. Future studies should further investigate the nature of this phenomenon.

In synthesis, results contribute to understanding beliefs and values that support parental behavior. This is due, in the first place, to scarcity of research on parental expectations for children with disabilities, specifically with DS. In second place, is due to the lack of studies including fathers as objects of research.

For further research, it is suggested to investigate other aspects such as comparing parental expectations on children with Down syndrome and other disabilities such as autism. Papers of this nature are still rare in the Brazilian context. Besides, it is necessary to do comparative studies on parental beliefs and values in families of children with Down syndrome, at different ages, aiming to find a variation (or not) on parental expectations during the course of development. That fact refers to the need for longitudinal studies. It is possible to understand that since the child grows he/she will transit through other not so familiar areas and the potential tensions that may come up from new situations need to be managed positively. Parents’ perspectives anticipating interactions in new environments may interfere in the way they implement the strategies.

Due to the fact that the sample of children who participated in the present study was attending a specialized institution for people with disabilities, it is worth believing that it may have contributed to the predominance of values about children’s independence. In these contexts, families receive guidance from professionals to encourage children’s autonomy and encourage parents to believe in the potential development of their children with Down syndrome. Therefore, it is worth emphasizing the importance of studies addressing schools and specialized care institutions for people with Down syndrome in order to ascertain values that permeate the contexts and their influence on children’s development.

REFERENCES


