Article

Models of Self in Families of People with Spina Bifida[1]

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Abstract: Models of self reveal cultural views regarding the competences that children should acquire, and these views tend to be shared by people within the same environment. Thus, this study aims to evaluate the models of self in families of people with spina bifida. Seventeen caregivers answered an online questionnaire containing socio-demographic questions and three scales of self: autonomous, related and autonomous-related. The data were analyzed using descriptive statistics and techniques of multivariate analysis. The main results indicate that the most valued model of self was the autonomous-related model, reflecting the desire that children develop autonomy as well as interpersonal relationships. Such a model, however, is distinct from that of family groups of people with typical development living in the same cultural environment, indicating the need for families of people with spina bifida to receive support to reach their developmental goals.

Keywords: spinal cord, family relationships, self-representations

Modelos de Self em Famílias de Pessoas com Espinha Bífida

Resumo: Os modelos de self revelam a visão cultural acerca das competências que as crianças devem adquirir e tendem a ser compartilhados pelas pessoas que integram o mesmo ambiente. Neste sentido, este estudo objetiva avaliar os modelos de self em famílias de pessoas com espinha bífida. Dezessete cuidadores responderam um questionário virtual contendo questões sociodemográficas e três Escalas de Self: Autônomo, Relacionado e Autônomo Relacionado. Os dados foram tratados por meio de estatística descritiva, com técnicas de análises multivariadas. Os principais resultados indicam que o modelo de self mais valorizado foi o autônomo relacional que se reflete no desejo que os filhos e filhas desenvolvam a autonomia e, também, relacionamentos interpessoais. Tal modelo, porém, distingue-se dos grupos familiares de pessoas com desenvolvimento típico que residem no mesmo ambiente cultural, o que evidencia a necessidade das famílias de pessoas com espinha bífida receberem apoio para alcançarem seus alvos desenvolvimentais.

Palavras-chave: medula espinhal, relações familiares, representações de si

Modelos de Self en Familias de Personas con Espina Bífida

Resumen: Los modelos de self revelan la visión cultural de las habilidades que los niños deben adquirir y suelen ser compartidos por personas que pertenecen a un mismo entorno. Así, este estudio tiene como objetivo evaluar los modelos de self en familias de personas con espina bífida. Diecisiete cuidadores contestaron un cuestionario virtual que contiene preguntas demográficas y tres Escalas de Self: Autónomo, Relacional y Autónomo-relacional. Los datos fueron analizados mediante estadística descriptiva, con las técnicas del análisis multivariado. Los principales resultados indican que el modelo de self más valorado es el autónomo relacional, que se refleja en el deseo de que los hijos e hijas puedan desarrollar la autonomía y también las relaciones interpersonales. Este hallazgo es distinto de los grupos familiares de personas con desarrollo típico del mismo entorno cultural. Por eso, las familias de personas con espina bífida deben recibir apoyo para lograr sus objetivos de desarrollo.

Palabras clave: medula espinal, relaciones familiares, representaciones del si mismo

The development of self is mediated in part by the beliefs that parents adopt (Kağitçibaşi, 2007; Keller, 2007, 2012). Considering adaptations to ecological conditions, models of self reflect cultural views regarding the competences that children should acquire, and these views tend to be shared by groups of individuals within the same environment (Keller, 2007). From this perspective, the present study aims to evaluate the models of self in families of people with spina bifida. The aim is thus to verify which development trends are valued, given the presence of a child with a disability.

The orientation of self depends on cultural context and can lead to different trajectories. In her cross-cultural study, Keller (2007) investigated two main trends: independent and interdependent models. Adults with a high level of education and few children living in urban environments in industrialized societies follow the independent model. The author highlights Germany as a context characteristic of this prototypical model because it is characterized by a high level of formal education

and a lifestyle based on freedom, individual achievements and choices, among other aspects. In this context, individuals are expected to become self-sufficient, competitive, assertive and holders of personal opinions (Keller, 2007). In turn, groups living in rural environments characterized by limited formal education, early parenthood and high fertility represent the interdependent model (Keller, 2007). In this perspective, in non-urban contexts there is a tendency to develop an interdependent self that prioritizes building close ties, while in urban contexts, there is a tendency to construct a self oriented towards independence.

Additionally, Kağıtçıbaşı (2007, 2012) proposes that autonomy and relationship can coexist in the same environment and therefore as complementary dimensions. For the author, the orientation of self varies in terms of agency (related to the degree of autonomy) and interpersonal distance (related to the degree of closeness with others) characterizing the autonomous-related model. This case is prevalent in families living in environments still in the process of modernization, such as developing countries, exemplified by Brazil.

The evidence of such models helps not only to gain knowledge regarding the orientations of self but also refers to socialization goals, defined as parents' desires and expectations regarding their children's future (Greenfield, Keller, Fuligni, & Maynard, 2003; Keller, 2007). In fact, these goals are derived from cultural models and mediate between these models and concrete parenting practices, that is, parental behaviors considered culturally appropriate (Keller, 2007; Keller & Kärtner, 2013). In the independent model, primary goals of socialization include the wish that children be able to be alone and demonstrate self-confidence and autonomy in decision making. In the interdependent model, these goals include demonstration of respect for elders and a life lived in harmony with family and community. With regard to the autonomous-related model, goals reflect the requirements of the globalized world, where children are expected to be able to both act independently as well as relate and cooperate in a social environment. This model can thus be a tool for socioeconomic transformation in developing countries (Kağıtçıbaşı, 2007, 2012; Keller, 2007).

The theoretical concepts presented have been tested in different cultural contexts. Friedlmeier, Schäfermeier, Vasconcellos and Trommsdorff (2008) conducted a study on socialization goals in Brazil and Germany with caregivers in a nursery and mothers of five-year-old children. The main results showed that the German participants exhibited preferences for individualistic goals, mainly regarding autonomy and tolerance. In turn, Brazilian participants prioritized the category of goals oriented towards discipline and initiative of the child, in particular.

Another study aimed to understand, among other issues, the socialization goals of Italian mothers and of African mothers who migrated to Italy (Carra, Lavelli, Keller, & Kärtner, 2013). The results showed that the former emphasized goals related to psychological autonomy and distal parenting style, while immigrant mothers valued goals in the related model and a proximal parenting style. In addition, there was a significant association between the socialization goals and parenting strategies of Italian mothers but not of immigrant mothers, suggesting that the latter were undergoing reorganization in the elaboration of their practices and beliefs (Carra et al., 2013).

Another study based on the cultural models of independence and interdependence was conducted to compare socio-demographic and psychosocial characteristics and maternal belief characteristics in two different contexts in Brazil, one in the southeast region and another in the northeast region (Vieira, Martins, & Lordelo, 2013). Participants included 112 mothers, who answered an individual questionnaire of closed questions and scales addressing demographic information, relationship and support, among others. The results showed that the autonomous-related model was predominant in both contexts based on socialization goals and beliefs regarding care practices. However, socio-demographic differences, such as educational level and the number of children in the families, influenced the responses, indicating that mothers who lived in the capitals valued independence more highly, while mothers from smaller cities placed more value on interdependence.

For Kağıtçıbaşı (2007) and Keller (2007), the influence of different socioeconomic factors on parental ideas and perceptions are evident. Other authors (Kobarg, Kuhnen, & Vieira, 2008; Sachetti, 2009; Seidl-de-Moura et al., 2008) also report effects based on population size, maternal education, social level, type of economy, and rural vs. urban environment. Accordingly, parental perspectives were found to depend on the structure of the physical and social environment and to be revealed in the care provided to children.

According to the previously mentioned aspects, knowing the models of self that parents establish is a fundamental task for understanding development, particularly of children and youth. This task, however, is challenging in regard to people with spina bifida. The characteristics of this condition can compromise parental expectations and the resources they use to overcome difficulties related to the development of children with disabilities (Nuernberg, 2008).

Described as the second most common congenital disorder in the world (Mersereau et al., 2004), spina bifida has an incidence of one in 1,000 live births in the United States and between 1.5 and 3 per 1,000 births in Europe. It is in a congenital malformation of the central nervous system due to incomplete closure of the neural tube. The most severe and common form is called myelomeningocele, characterized by the extravasation of the cord and/or nerve roots due to the total or partial absence of the posterior arch of some vertebrae (Gaíva, Neves, & Siqueira, 2009).

Spina bifida can occur in any region of the spinal cord, at the thoracic, lumbar and sacral level. The lower the site of the malformation, the better the functional performance and motor development of the lower limbs (Bartonek, 2010). People affected may exhibit various disabilities resulting from neurological injury, such as hydrocephalus. This typically entails difficulties in cognitive areas and, consequently, in school performance (Fletcher & Brei, 2010). Additionally, neurogenic bladder, bowel dysfunction, paralysis of the lower

limbs and psychosocial disorders, for example, may also occur (Gaíva, Corrêa, & Espírito Santo, 2011). Generally, treatment is surgical, aiming at correcting the neural tube in order to preserve the cord function, reduce the risk of infection and promote the development of the baby. Often, additional surgeries are required as well as substantial medical care throughout life (Assis & Martinez, 2011; Gaíva et al., 2011).

Considering the characteristics and the commitments arising from such neurological injury, it is important to investigate the adjustments made by families of people with spina bifida, including whether their perspectives on the development of self are focused on autonomy and/or relationship. According to the study by Gaíva et al. (2009) on the experience of mothers of children with spina bifida with daily care, it was found that parents harbored an optimistic perspective of the future. They hoped that their children would be able to walk and grow up enjoying a good quality of life.

This desire for motor gains was also mentioned in families of people with other disabilities. In the study by Wiart, Ray Darrah and Magill-Evans (2010), data showed that the main parental goals for children with cerebral palsy were related to the range of movements contributing to functional success, beyond the desire that children have good health, physical fitness and social acceptance. In contrast, Sousa, Ribeiro and Melo (2009) conducted a survey of parents of children with Down syndrome. The main results showed that family members expected their children to be independent and exhibit motor development allowing them to move with ease and practice sports.

Despite these parental perceptions, the literature shows that compared with families of people with typical development, parents of people with spina bifida tend to be at a disadvantage. For example, these parents experience higher levels of stress in executing their parental role (Vermaes, Janssens, Mullaart, Vinck, & Gerris, 2008), feel more socially isolated and less optimistic regarding the future of their children (Grosse, Flores, Ouyang, Robbins, & Tilford, 2009), are overprotective and have less desire for their children to develop autonomy in the future (Holmbeck et al., 2002). Thus, these parents feel less satisfied and capable, which may be associated with lower confidence in the development of people with spina bifida (Holmbeck & Devine, 2010).

In turn, when compared with people with typical development, children and adolescents with spina bifida tend to be more socially isolated and exhibit immature and passive behavior, which appears to persist over time (Holmbeck et al., 2010). In this respect, a study on life satisfaction involving youth with spina bifida in Germany (Barf et al., 2007) revealed that social participation was limited, due to accessibility obstacles, emotional barriers and financial and motor limitations. In addition, they tended to be less satisfied with partnership relationships and social activities in which they participated. Despite these difficulties, the young participants with spina bifida and hydrocephalus were satisfied with family life, although they were less satisfied with self-care ability and social relations (Barf et al., 2007).

The studies on spina bifida indicate that although there are parenting ideas and desires culturally shared in the German context, these ideas and desires are challenged by the conditions experienced by children with disabilities. According to Andrade, Vieira and Dupas (2011), the particularities of the health conditions of these children interfere with the ideas of caregivers, often reflecting difficulties coping with daily needs and the very relationship that parents establish in relation to the disability. In this case, parental conceptions of development, including the orientation of self they adopt, may be affected, as their beliefs are permeated by uncertainty regarding the future of their child (Gondim & Carvalho, 2012).

Moreover, although numerous studies highlight the German environment as representative of the model of independent self, little is known regarding how parents invest in the trajectory of children and adolescents with disabilities in Germany. Thus, the research from which this article is derived aimed to evaluate the models of self that German families adopted in relation to their children with spina bifida, seeking to contribute to the understanding of the complexity of contextual and personal characteristics that mark the perception of parents regarding their children's atypical development.

Method

Participants

Seventeen German families, selected based on the criteria of residence in Germany and possessing a child with spina bifida who was aged from zero to 20 years old, participated in the study.

Instruments

Two instruments were used: (a) an interview script consisting of questions regarding socio-demographic characteristics (age, gender, educational level, family income, level of spina bifida and the presence of hydrocephalus); and (b) the *Scales of Autonomous Self, Related Self, and Autonomous-Related Self* (Kağitçibaşi, 2007), consisting of 27 statements followed by a five-point Likert-type scale (ranging from "strongly disagree" to "strongly agree"). After testing an early version of 40 items with a sample of university students in Turkey, Kağitçibaşi (2007) devised a new version with 27 items, which was submitted to a concurrent validity and construct analysis with a sample of 677 subjects. The results showed that the scales are valid for assessing the models of autonomous, related and autonomous-related selves, with Cronbach's alphas of .74, .78 and .84, respectively. Finally, several cross-cultural applications were conducted with college students in Belgium, Germany, Hong Kong, Turkey, the United Kingdom and the United States, confirming good levels of reliability and internal consistency (Kağitçibaşi, 2007). Statements include "I feel independent of the people who are close to me," "I need the support of persons to whom I feel very close," and "I think often of those to whom I feel very close."

Procedure

Data collection. The research occurred in a virtual environment using online questionnaire software (*Survey Monkey*) that offers tools for virtual data collection and analysis. The link to access the survey was posted on the following sites: School of Rehabilitation Sciences, University of Dortmund (www.fk-reha.tu-dortmund.de); German Association for Spina Bifida and Hydrocephalus (http://www.asbh.de); and *Sternchenforum*, an online help service for families and people with spina bifida and hydrocephalus, which operates in partnership with this association (www.sternchenforum.de).

Data analysis. Data were transcribed and processed using the Statistical Package for Social Sciences (SPSS) software. The interview script was analyzed using descriptive statistics. The results were crossed with the Scales of Autonomous Self, Related Self, and Autonomous-Related Self (Kağitçibaşi, 2007) using the chi-square non-parametric test, with a 5% significance level.

Subsequently, the scales data were subjected to evaluation of the items' reliability in order to apply factorial analysis (FA). This procedure enables the analysis of a better set of items, namely, the optimal loads to compose the scores of the Scales of Autonomous Self, Related Self, and Autonomous--Related Self (Kağitçibaşi, 2007). Initially, the reliability of the items was evaluated using Cronbach's alpha coefficient, and an $\alpha = .79$ was obtained for the 27 studied variables. This value demonstrates that the scales used are consistent and satisfactory for the use of FA, as the result is greater than the cutoff, which is $\alpha = .70$.

Shortly thereafter, the feasibility of factor analysis was evaluated based on the correlation matrix. A substantial number of correlations over .30 were found, suggesting possible interrelations among the variables. This procedure provides an adequate basis for proceeding to the next step, the empirical examination of the adequacy of FA with respect to a general base and each variable.

Next, the overall significance of the correlation matrix was evaluated using Bartlett's sphericity test, which yielded $p = .0001$. However, this step tests only for the presence of non-zero correlations, not for the pattern of these correlations. Thus, to test whether any feature from the various items of the scale have a possible relationship in common, the Kaiser--Meyer-Olkin test (KMO) was used, and an acceptable range for use of the technique (.79) was found.

After verifying that it was possible to apply FA, the factor analysis with regard to the scales data was conducted using the mathematical method of principal components and factor extraction by varimax-type orthogonal rotation. The criteria adopted for selecting the number of factors to be extracted were the latent root criterion (eigenvalue greater than 1) and the percentage of explained variance (sum of explained variance).

It was found that a model with seven factors would be appropriate to represent the initial covariance structure and would explain 87.3% of the total variance of the original items. The factors were called "autonomous-related," consisting of six items; "autonomous," containing five items; "related," with four items; and "extra," with six items. The "autonomous," "related" and "autonomous-related" factors were loaded with the scale's original items. The "extra" factor, in turn, is composed of items that relate to all three mentioned scales. Based on the factors found, the measure of sampling adequacy (MSA) test was conducted. Each of the variables in the study generated an MSA above .50, indicating that the factors found in the FA adequately described the variation of the original data.

Finally, the index of each participant in the Scales of Autonomous Self, Related Self, and Autonomous-Related Self (Kağitçibaşi, 2007) was calculated. The calculation was performed by multiplying the factor weights by the individual values assigned to items of the mentioned scales, which were derived from the analysis of principal components. Each index is interpreted according to a standardization of the values obtained, so that they can be classified from 0 to 1 or from 0 to 100%. Data from the indices were classified according to the theory of sample percentiles (Morettin & Bussab, 2011).

Ethical Considerations

This research was initially approved by the faculty committee of the School of Rehabilitation Sciences of the University of Dortmund and the administrative board of the German Association of Spina Bifida and Hydrocephalus. Approval by the mentioned institutions is considered a sufficient ethical procedure for the development of scholarly works in Germany, such as the one presented here.

Results

The results are presented in two parts. First, descriptive statistics, which involve the socio-demographic characteristics of the participants, are addressed. Subsequently, the results of the Scales of Autonomous Self, Related Self and Autonomous-Related Self (Kağitçibaşi, 2007) are presented, using the FA and the indices.

Socio-demographic characteristics

Regarding the socio-demographic characteristics, the age of the parents ranged from 25 to 54 years, with a mean of 36.84 years ($SD = 7.27$). The age of the children ranged from 0 to 20, with a mean of 7.87 years ($SD = 7.09$). With regard to the gender of children, 13 were female, and four were male.

Regarding the affected spinal region, there was prevalence of spina bifida at the lumbar level (9), followed by the thoracic (4) and sacral (2) levels and level not specified (2). Hydrocephalus was present in most cases (16), except for one son and one daughter. Finally, the most frequent range of family income was from 2,001 to 3,500 euros (9), followed by 500 to 2,000 euros (4), 3,501 to 5,000 euros (2) and over 5,000 Euros (1).

Application of factorial analysis

Table 1 shows the factor loadings, eigenvalues and percentages of explained and accumulated variances calculated using the varimax-type orthogonal rotation method. It was noted that a model with seven factors would be sufficient to represent the initial covariance structure, as it explained 87.3% of the total variability of the original items. Factor 1 explains 24.38% of the total variability; Factor 2, 14.54%; Factor 3, 10.56%; Factor 4, 10.53%; Factor 5, 10.44%; Factor 6, 8.83%; and Factor 7, 7.97%.

Table 1

Factorial Loadings, Eigenvalues, Percentages of Explained and Accumulated Variances

Scales Of Self	Items	Factors							Commu nalities	Cronbach's alpha
		F1	F2	F3	F4	F5	F6	F7		
Autonomous-related	19	.915	.002	-.048	-.006	-.126	.104	-.204	.915	
	21	.903	.151	.048	-.076	-.009	-.015	.190	.882	
	23	.897	-.050	-.156	.061	.291	.120	.119	.949	.82
	24	.944	-.019	-.023	-.051	-.082	-.108	-.141	.932	
	25	.540	.019	-.022	.445	-.377	-.156	-.189	.702	
	26	.643	.021	-.027	-.071	.603	-.259	-.240	.921	
Autonomous	2	-.404	.658	-.123	.065	.245	.084	.352	.806	
	3	.141	.658	.523	-.041	.324	-.125	.060	.852	
	4	-.469	.720	.034	.318	.155	-.054	-.089	.875	.79
	5	.272	.800	.283	-.186	-.008	-.072	-.063	.837	
	7	.447	.711	-.089	-.156	-.051	.250	-.099	.813	
Related	11	-.016	-.071	.935	.116	.115	.030	-.007	.907	
	13	.234	-.403	-.751	.153	.017	.254	.103	.879	
	16	-.154	-.186	-.013	.848	-.294	-.026	.173	.894	.75
	18	.038	.068	.000	.948	.089	-.026	-.084	.908	
	1	-.135	.375	.526	-.361	.579	.077	.156	.931	
	15	.057	-.132	-.144	.056	-.915	-.137	-.084	.908	
Extra	8	-.217	.114	-.093	-.095	.138	.885	.241	.939	
	12	.476	.067	-.223	.129	-.217	.595	-.251	.762	.80
	22	-.127	.336	-.133	.131	-.187	-.634	.505	.855	
	20	-.023	-.058	.000	-.015	.078	.031	.931	.878	
Square Sum of Eigenvalues		5.21	3.05	2.22	2.21	2.19	1.84	1.67	18.32	
										.79
Percentage of Explained Variance (trait)		24.4	14.5	10.6	10.5	10.4	8.83	7.97	87.27	

With the results obtained in Table 1, the variables that have more influence on each factor were identified, namely, those having the highest factor loadings. Factor 1 was observed to have higher weights or higher factor loadings for the items, "It is important to have both close relationships and also to be autonomous," "A person who has very close relationships cannot make his/her own decisions," "Giving importance to the opinions of those who are close to me means ignoring my own opinions," "Being very close to someone prevents being independent," "A person can feel both independent and connected to those who are close to him/her," and "In order to be autonomous, one should not form close relationships."

Regarding Factor 2, the highest weights were observed for the variables: "I do not like a person to interfere with my life, even if he/she is very close to me;" "I feel independent of the people who are close to me;" "I lead my life according to the opinions of people to whom I feel close;" and "The opinions of those who are close to me influence me on personal issues."

In turn, Factor 3 had the highest weight for the variables, "I prefer to keep a certain distance in my close relationships," and "The people who are close to me strongly influence my personality." Regarding Factor 4, the most significant weights were in the variables, "Those who are close to me are my top priority," and "I do not share personal matters with anyone, even if very close to me." All the items of these first four factors comprise the same factors in the original scale.

According to the information regarding Factor 5, weights were found in the variables, "People who are close to me have little influence on my decisions," and "I do not worry about what people think of me, even if they are close to me." Factor 6 had higher weights in the variables, "I usually try to conform to the wishes of those to whom I feel very close," "Generally, I keep personal issues to myself," and "A person should be able to oppose the ideas of those who are close."

In Factor 7 only item 21 had a higher weight: "Even if the suggestions of those who are close are considered, the last decision should be one's own."

Subsequently, the chi-square correlation test was performed to detect possible associations between the Scales of Autonomous Self, Related Self, and Autonomous-Related Self and data from the sample characterization interview (Kağitçibaşi, 2007). Values of $p < .05$ were considered as criteria. Thus, it was observed that the gender of the sons and daughters was associated with the Scales of Autonomous Self and Related Self for the following items, respectively: "I prefer to keep a certain distance in my close relationships," and "I usually try to conform to the wishes of those to whom I feel very close." There was also an association between the age group and Scale of Autonomous Self, particularly for items "I do not like a person to interfere with my life, even if he/she is very close to me," "The opinions of those who are close to me influence me on personal issues," "On personal issues, I accept the decisions of people to whom I feel very close," and "I usually try to conform to the wishes of those to whom I feel very close."

Another significant result occurred between income and the following items of the Scale of Related Self: "My relationships to those who are close to me make me feel peaceful and secure," and "I do not share personal matters with anyone, even if very close to me." In addition, significant values were found for income and items of the Scale of Autonomous-Related Self: "A person who has very close relationships cannot make his/her own decisions," and "A person can feel both independent and connected to those who are close to him/her."

Factorial scores (indices)

Table 2 shows the standardized scores and the general indices of each participant per scale. For the Autonomous Self, scores led to indices ranging from 20% to 81%. On the Scale of Related Self, indices were in a range of 28% to 90%. The Scale of Autonomous-Related Self, in turn, showed indices ranging from 46% to 92%. Therefore, in general, the participants attributed the lower indices to children's orientation towards autonomy, while higher indices were attributed to orientation towards the autonomous-related tendency.

Table 2

Standardized Scores and General Indices of each Participant per Scale

| ID | Autonomous Scale of Self | | | | | Related Scale of Self | | | | | Autonomous-Related Scale of Self | | | | |
| | Standardized Scores | | | Index | % | Standardized Scores | | | Index | % | Standardized Scores | | | Index | % |
	Fact1	Fact2	Fact3			Fact1	Fact2	Fact3			Fact1	Fact2	Fact3		
P1	.585	.302	.189	.36	36	.820	.282	.933	.68	68	.889	.894	.992	.92	92
P2	.237	.789	.141	.39	39	1,000	.445	.000	.51	51	.000	.935	.919	.52	52
P3	.120	.565	.357	.35	35	.866	.939	.897	.90	90	.807	.933	1,000	.90	90
P4	.334	.360	.457	.38	38	.185	.468	.834	.48	48	.669	1,000	.000	.58	58
P5	.459	1,000	1,000	.81	81	.573	.342	1,000	.63	63	.926	.810	.818	.86	86
P6	1,000	.932	.007	.66	66	.923	.320	.175	.49	49	.571	.000	.750	.46	46
P7	.415	.000	.489	.30	30	.834	.402	.948	.73	73	.784	.914	.966	.87	87
P8	.574	.507	.371	.49	49	.345	.518	.864	.56	56	.863	.621	.785	.77	77
P9	.466	.688	.154	.44	44	.000	.478	.727	.38	38	.776	.385	.785	.67	67
P10	.149	.729	.412	.43	43	.522	.597	.623	.58	58	.488	.713	.816	.64	64
P11	.473	.401	.387	.42	42	.925	.646	.789	.79	79	.889	.894	.992	.92	92
P12	.588	.870	.301	.59	59	.229	.000	.727	.31	31	.926	.810	.818	.86	86
P13	.000	.603	.000	.20	20	.877	.759	.994	.87	87	1,000	.642	.470	.75	75
P14	.357	.639	.254	.42	42	.174	1,000	.041	.41	41	.884	.619	.984	.84	84
P15	.294	.730	.303	.44	44	.265	.836	.593	.56	56	.734	.595	.792	.71	71
P16	.079	.790	.422	.43	43	.300	.930	.987	.72	72	.926	.810	.818	.86	86
P17	.917	.472	.490	.63	63	.192	.208	.469	.28	28	.863	.621	.785	.77	77

Note: ID = Participants; FACT1 = Factor 1; FACT2 = Factor 2; FACT3 = Factor 3.

This tendency of orientation towards an autonomous-related self by family members is also presented by the classification into five different groups according to the theory of

sample percentiles (Morettin & Bussab, 2011). In this case, the following criteria were followed: Group 1 - Parents with scores from 0 to 50%; Group 2 - Parents with scores from 51

to 70%; Group 3 - Parents with scores from 71 to 80%; Group 4 - Parents with scores from 81 to 90%; and Group 5 - Parents with scores from 91 to 100%.

Regarding the Scale of Autonomous Self, most participants (16) had rates classified in groups 1 and 2, namely, they placed less importance on the dependence of children. Similarly, with respect to the Scale of Related Self, most parents (12) were classified in groups 1 and 2, so that building close bonds was less prioritized. Regarding the Scale of Autonomous-Related Self, it was found that most parents (12) showed high rates in groups 3, 4 and 5, valuing the goals that cover both tendencies.

Discussion

The results of the study help describe phenomena related to the development of self by parents who have a child with spina bifida. The Cronbach's alpha that was found (. 79) and most of the factors from the FA, proved to be valid for the assessment of the three models of self, consistent with the theory (Kağitçibaşi, 2007). Thus, the combination of items that constitute the first factor belongs to the Scale of Autonomous-Related Self. The items forming part of the second factor belong to the Scale of Related Self. The combination of items of factors 3 and 4 belong to the Scale of Related Self. Factors 5, 6 and 7, however, were classified as extra, as they did not fit exclusively into any of the previous scales.

Additionally, there was a significant association between the items of the Scale of Autonomous Self with the children's gender and age group. Moreover, family income was associated with both the Scale of Related Self and Related Autonomy. These results show possible influences of socioeconomic characteristics on the model of self that parents establish. This result is consistent with Kağitçibaşi (2007) and Keller (2007), who reported the effects of different socioeconomic factors on parental ideas and perceptions as being evident. The findings also agree with other studies of typical families, where parental beliefs vary according to socioeconomic status, including population size and mothers' education (Kobarg et al., 2008; Sachetti, 2009; Seidl-de-Moura et al., 2008).

In turn, the affected spinal region and the presence of hydrocephalus appear to have little effect in models of self that parents develop, as no association between them was identified. It is possible that the tests performed with these variables were not very sensitive to the degree of commitment that these injuries entail, such as physical, cognitive and school performance limitations, as Bartonek (2010) and Fletcher and Brei (2010) claim.

According to the general indices found, the model of autonomous self was less valued. This finding contrasts with that of the families of persons with typical development residing in Germany, considered the prototype of the autonomous model (Keller, 2007). In this sense, it appears that the belief of participants in this study had to conform to the development limitations of their children with spina bifida, leading them to reframe or break with the model of self shared by the society in which they live.

In this respect, these results appear to agree with Holmbeck et al. (2002), who state that parents of people with spina bifida have less desire for their children to develop autonomy. In another context, these results may be related to the fact that parents are less optimistic regarding the future of their children, as Grosse et al. (2009) state. It may also reflect the fact that parents feel less satisfied and competent and less confident in the development of people with spina bifida, as reported by Holmbeck and Devine (2010).

However, the orientation towards independence was not completely ignored, as its characteristics are also included in the autonomous-related model. This model achieved the highest scores and covers an orientation of self that meets the demands of the globalized world, such as the ability to act autonomously, while remaining able to relate to others, as Kağitçibaşi (2007, 2012) suggests. It is, according to this author, a tendency found in developing countries and does not theoretically represent the German environment.

Given that the sample includes families of people with atypical development, the great value placed on to the autonomous-related model of self appears to show that social and economic class or education level were not major references in establishing the orientation of self. Their beliefs may also depend on the disability conditions of their child and the limitations resulting from neurological damage, as shown by Fletcher and Brei (2010) and Gaíva et al. (2011).

In fact, although the autonomous-related self seeks to meet the requirements of independence and relationships arising from modernization, it might have prevailed because of parental concerns regarding the trajectory of their child with spina bifida. For example, in relation to independence, there may be a search for self-care skills, an aspect that generated lower satisfaction in the study by Barf et al. (2007). Moreover, it is likely that there is a desire to improve motor gains, as evidenced in the study by Wiart et al. (2010) with parents of children with cerebral palsy and in the study by Sousa et al. (2009) with parents of children with Down syndrome. In turn, the high value placed on relationships may be due to the confrontation with the social barriers that people with disabilities face on a daily basis. This aspect is justified by research that found that children and adolescents with spina bifida tend to be more socially isolated and less satisfied with partnership relationships and social activities in which they participate (Barf et al., 2007; Holmbeck et al., 2010).

Thus, the search for the model of self has been studied in different cultural contexts, and this study sought to address it by analyzing families of people with disabilities. The study's findings suggest that participants conformed to the demands of their children with spina bifida, confirming that the presence of children or adolescents with developmental alterations requires the adoption of strategies that allow achieving established ideals (Leyendecker, Lamb, Harwood, & Schölmerich 2002).

Accordingly, parents' beliefs produced an orientation of self towards the demands of being responsible for a disabled person. In practical terms, the families appeared to invest in resources and behaviors that develop the autonomy and relationships of their children with spina bifida, despite the un-

certainties regarding the future (Gondim & Carvalho, 2012). Thus, the models of self valued the most by the participants demonstrate parenting practices compatible with the disability situation they are experiencing, although different from the family groups of people with typical development residing in the same cultural environment (Keller, 2007).

Emphasis is given, nevertheless, to the importance that such families receive social support in an attempt to secure their goals. According to Minetto, Crepaldi, Bigras and Moreira (2012), social support networks are essential for families of children with atypical development, particularly to reflect upon their educational practices. Therefore, such support may serve as an ally to families, in particular, in the implementation of practices that enhance child development.

The findings are restricted to the studied sample. Other limitations include the number of participants and the use of an instrument not specifically aimed at families of people with atypical development, such as spina bifida. In terms of future research, it is recommended to evaluate the models of self and goals, taking into account other cultural environments and other developmental disorders. It will thus be possible to advance knowledge regarding the beliefs that guide how parents invest in the trajectory of children and adolescents with disabilities.

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