

CORRELATION BETWEEN MARITAL RELATIONSHIP, FAMILY ROUTINE, SOCIAL SUPPORT, NECESSITIES AND QUALITY OF LIFE OF PARENTS AND MOTHERS OF CHILDREN WITH DISABILITY^{1, 2}

CORRELAÇÃO ENTRE O RELACIONAMENTO CONJUGAL, ROTINA FAMILIAR, SUPORTE SOCIAL, NECESSIDADES E QUALIDADE DE VIDA DE PAIS E MÃES DE CRIANÇAS COM DEFICIÊNCIA

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ABSTRACT: Considering the importance of families for child development and that fathers and mothers of children with disabilities can live parental experience in a differentiated way, this research aimed to correlate the marital relationship with the family routine; quality of life, parental needs and satisfaction with social support received. The research was developed with 120 participants, 60 mothers and 60 fathers of children with intellectual disability, physical disability, autism and delay in child development, aged from 0 to 6 years. The following instruments were used to collect data: *Marital Relationship Questionnaire*, *Inventory of resources in the family environment*, *Questionnaire on family needs*, *Abbreviated questionnaire on quality of life*, and *Social support questionnaire*. Pearson's correlation test was used to analyze the data. The results showed that the greater the resource of the family environment the better the marital relations between the parents and the smaller the acceptance of the negative characteristics of the spouse. As for the needs of the participants, the better the spouse's evaluation of the partner, the lower the needs of the parents. In relation to social support and marital relationship, it was observed that the more the parents presented characteristics that did not please their spouse, the smaller the social supports available to them. This study may contribute to the knowledge about the family institution, which is little considered in public policies and social projects, which persist in assistencialism and do not perceive the family as a unit.

KEYWORDS: Special Education. Families. Child. Disability.

RESUMO: Considerando a importância das famílias para o desenvolvimento infantil e que pais e mães de crianças com deficiência podem vivenciar a experiência parental de forma diferenciada, esta pesquisa teve por objetivo correlacionar o relacionamento conjugal com a rotina familiar; qualidade de vida, necessidades parentais e satisfação com suporte social recebido. A pesquisa foi desenvolvida com 120 participantes, sendo 60 mães e 60 pais de crianças com deficiência intelectual, deficiência física, autismo e atraso no desenvolvimento infantil, com idade entre 0 a 6 anos. Para a coleta de dados, foram utilizados os seguintes instrumentos: *Questionário de Relacionamento Conjugal*, *Inventário de recursos no ambiente familiar*, *Questionário sobre as necessidades das famílias*, *Questionário abreviado da qualidade de vida* e *Questionário de suporte social*. Para a análise dos dados, utilizou-se o teste de correlação de Pearson. Os resultados demonstraram que, quanto maior era o recurso do ambiente familiar, melhores eram as relações conjugais entre os pais e menor era a aceitação das características negativas do cônjuge. Quanto às necessidades dos participantes, quanto melhor era a avaliação do cônjuge ao companheiro, menores eram as necessidades dos pais. Em relação ao suporte social e relacionamento conjugal, tem-se que, quanto mais os pais apresentavam características que não agradavam seu cônjuge, menores eram os suportes sociais disponíveis a eles. Este estudo pode contribuir para o conhecimento acerca da instituição familiar, que é pouco considerada nas políticas públicas e nos projetos sociais, que persistem no assistencialismo e não percebem a família como uma unidade.

PALAVRAS-CHAVE: Educação Especial. Famílias. Criança. Deficiência.

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1 INTRODUCTION

The family concept is not ideally configured, since there are numerous combinations of interaction between the individuals that constitute different types of families, denominated as follows: (a) nuclear or traditional, (b) remarried, (c) single parent (father or mother), (d) homosexuals, among others (Stratton, 2003).

Family patterns are changing and reabsorbing the psychological, social, political, economic and cultural changes, provoking the evolution and updating of its history, which requires accommodations and adjustments when facing the social realities (Kreppner, 2000; Stratton, 2003).

Since the mid-twentieth century, families have been going through significant changes, the transition from rural to urban contexts is one of them. In addition, such changes are related to the emergence of new roles, to economic demands, to changes in tradition and to the diversity of the family constitution (Arriagada, 2000; Biasoli-Alves, 2000; Serrano, 2007; Dessen & Silva, 2008).

Women, by introducing into their routine the role of professional as well as mother, have led to changes in marital and parental relationships, fostering greater participation of the father in the care and social context of the child (Dessen & Braz, 2000).

Regardless of the social transformations that occurred in the middle of the twentieth century and the changes in the understanding and social representation of the meaning of being a father, today, active paternal involvement continues to be an important and decisive moment in the development of the child and the family (Souza & Benetti, 2009).

Both the paternal and the maternal involvement, that is, the involvement of the couple with the child becomes beneficial to him/her, since the parental roles and their influence become crucial components for the social-emotional development and the adjustment in diverse contexts of the individual. Therefore, researches involving parental practices should focus not only on mothers but also on fathers, as well as on the division of parental roles and their influence on the children's development (Cia, 2009).

The marital relationship influences child development and can be considered a risk factor for development when the child often experiences destructive conflicts between parents. On the other hand, constructive conflicts, in which parents enter into an agreement and dialogue, can bring positive models for future offspring social relationships (Fantinato, 2013). Thus, marital relationships influence parental behaviors, which may interfere with child development (Bolsoni-Silva & Marturano, 2010a; Fantinato & Cia, 2015).

Studies have shown that the quality of the marital interaction can influence the relationship between parents and children, as well as the behavioral repertoire of children, which can lead to problems in behavior or maintenance and development of socially skillful behaviors (Silva, 2000; Bolsoni-Silva & Marturano, 2010a; Fantinato & Cia, 2015).

According to Turnbull and Ruef (1996), the birth of a child can cause problems in the relationship between the couple and the extended family, especially when the child presents some type of disability, as it may require more attention and specific care. In fact,

parents, by dedicating more time to care for their child with disability, may end up harming the relationship and interaction as a couple.

Parental variables are fundamental resources for understanding families, especially those that coexist with children with disabilities, which often go through changes in family organization and functioning, which may generate a need to discover new strategies to deal with everyday situations that the child will demand.

According to Silva (2000), parents with greater agreement about educational practices are more likely to offer a more consistent education to their children. On the other hand, parents' marital problems are related to the emergence and maintenance of children's behavior problems, which may negatively influence children's social repertoire (Bolsoni-Silva & Marturano, 2010a).

There are several factors that influence child development. This study compares personal and family variables, between fathers and mothers. Regarding the personal variables, the marital relationship, the family routine, the parental needs and the satisfaction with social support received were investigated. In this sense, considering the importance of families for child development and that fathers and mothers of children with disabilities can experience parental involvement in a differentiated way, this research had the objective of correlating the marital relationship with the family routine; and the quality of life, parental needs and social support satisfaction received.

2 METHOD

2.1 DESIGN

This study followed the correlational design, in order to allow the comparison of the occurrence of variables in different moments or situations. It was important to understand joint occurrences of the phenomena, despite not establishing causal relationships (Cozby, 2006) of the independent variables of fathers' and mothers' groups of children with intellectual disability, physical disability, autism and delay in neuropsychomotor development (Pestana & Gageiro, 2005; Cozby, 2006).

2.2 PARTICIPANTS

This research was developed with 120 participants, consisting of 60 mothers and 60 fathers of children with intellectual disability, physical disability, autism⁶ and delay in neuropsychomotor development, in the age group from zero to six years. Children with developmental delay should attend an early stimulation center or multifunctional resource rooms (MRR).

Tables 1 and 2, below, present the characterization of the participants of the research, the mothers, the fathers and the children.

⁶ Law 12,764, of December 27, 2012, considers the individual with autism spectrum disorder as a person with a disability, for all legal purposes. For this reason, the terminology "child with disabilities" will be used for all the child population related to the parents participating in this study.

Characterization of participants	
Average age of mothers	33 years old
Average age of fathers	35 years old
Schooling Mothers	20% Illiterate 48% Incomplete Elementary School 10% Complete Elementary School 15% Incomplete High School 7% Complete Higher Education
Schooling Fathers	20% Illiterate 35% Incomplete Elementary School 14% Complete Elementary School 20% Incomplete High School 11% Complete High School
Brazil Criteria	18% B2 30% C1 40% C2 12% D-E

Table 1. Characterization of mothers and fathers of the G1 (Intellectual Disability); G2 (Physical Disability); G3 (Autism); and G4 (Neuropsychomotor Delay).

Note = Brazil Criteria Questionnaire (Brazilian Association of Research Companies [*Associação Brasileira de Empresas de Pesquisa - ABEP*], 2015). It is a questionnaire that evaluates the possession of durable consumer goods and the degree of education of the head of the household. The data provide the classification of purchasing power, which are divided into five classes (A, B, C, D and E). The classes A and B are subdivided into A1, A2, B1 and B2.

Children's characterization	
Gender	38 Male 22 Female
Average age of children	3 years old
Diagnostic	14 Down Syndrome 1 Child Batten Syndrome 11 Cerebral Palsy 2 Arthrogyposis 2 Myelomeningocele 15 Autism 15 Neuropsychomotor Delay
Children's schooling	13 Early Intervention 13 Preschool and Early Intervention 16 Preschool 4 Preschool and Special School 8 Special School 3 Nursery and Early Intervention 3 Elementary School (regular)

Table 2. Characterization of children.

2.3 DATA COLLECTION

The research project was approved by the Ethics Committee of the Federal University of São Carlos/UFSCar (CAAE: 44203115.1.0000.5504). The contact with the participants occurred in Institutions that serve the community resident of municipalities in the hinterlands of São Paulo. The institutions offer individual actions in different areas, such as physiotherapy in Neuropediatrics, Early Intervention, Occupational Therapy in Childhood Physical Dysfunction, Occupational Therapy in Child and Adolescent Mental Health, Psychology and Special Education teaching.

Data collection with parents took place in their preferred places, being developed in the child care centers, Special Education institution, or even in the home of the participants. The majority of the participants resided in two medium-sized municipalities, while one participant was a resident of a small municipality, in the hinterland of the state of São Paulo.

2.3.1 EVALUATION MEASURES FOR PARENTS

- **Short Questionnaire of The World Health Organization Quality of Life “WHOQOL-bref”** (translated and validated in Brazil by Fleck et al., 2000)

The WHOQOL-bref instrument is composed of 26 questions related to the values, aspirations, pleasures and concerns of the participant. The questions addressed in this instrument are based on time, situations that occurred in a period of up to two weeks.

Each question consists of alternatives from 1 to 5, which involve different options corresponding to the numbers, such as: (a) very bad, neither bad/nor good, good and very good; (b) very dissatisfied, dissatisfied, neither satisfied nor dissatisfied, satisfied, very satisfied; (c) nothing, very little, more or less/average, quite/very, extremely/completely; (d) never, sometimes, often, very often and always. The option that suits the reality of the subject must be ticked, and all alternatives must be answered by the participant.

- **Inventory of family environment resources - FER** (Marturano, 1999)

It is a semi-structured interview script that evaluates family environment resources that can contribute to academic learning in the Elementary School years. The resources refer to three areas: (a) resources that promote proximate processes; (b) activities that signal stability in family life; and (c) parenting practices that promote family-school linkage.

For this study, two questions were considered that could be applied to preschool children, as well as comparative analyzes could be carried out between parents and mothers: Routine in relation to the daily activities of the child (composed of eight items) – “Your child has the right time for” and family reunions (consisting of seven items) – “Your family is usually reunited”.

- **Marital Relationship Questionnaire** (Bolsoni-Silva & Marturano, 2010b)

This questionnaire evaluates questions about the marital relationship. It consists of 121 items, distributed in seven scales. It is a Likert-type scale that evaluates the characteristics of the behaviors and the frequency that they occur. To identify the characteristics and measure the frequency, there are three alternatives of response, namely: (F) frequently; (S) sometimes; and (N) never or almost never. The instrument allows to obtain the total score for each of the themes. This instrument showed good correlations in its test-retest.

- **Questionnaire on family needs - QNF** (Pereira, 1996)

It consists of 28 items, distributed in six topics: (a) information needs (7 questions); (b) need for support (7 questions); (c) explain to others (4 questions); (d) community services (3 issues); (e) financial needs (4 questions); (f) functioning of family life (3 questions). The answers of the questionnaire can be given between a scale of 1 to 3, being 1 (I don't need this kind of help); 2 (I'm not sure I need this kind of help) and 3 (I need this kind of help). This study demonstrated an excellent internal consistency ($\alpha = 0.90$).

- **Questionnaire on social support – QSS** (translated and validated in Brazil by Matsukura, Marturano, Oishi & Borasche, 2002)

In order to evaluate the social context in which the family is inserted, this instrument is composed of 27 questions that raise the number of sources of social support perceived (up to nine possibilities) and the level of satisfaction with each support (ranging from very satisfied to very dissatisfied). Other studies that use this instrument also showed good internal consistency (Gualda, 2015; Spinazola, 2017). In this study, the instrument had an excellent internal consistency ($\alpha = 0.94$).

2.4 DATA ANALYSIS PROCEDURE

To correlate the data, the Pearson correlation test was used. This test measures the degree, the direction of relations between continuous variables, and the degree to which two variables change together (Dancey & Reidy, 2018). It was used as significant $p < 0.05$.

3 RESULTS AND DISCUSSION

Below, the tables that evaluated the correlations between the following aspects: (a) Marital Relationship and Quality of Life; (b) Marital relationship and family routine; (c) Marital relationship and family needs; and (d) Marital relationship and satisfaction with social support. Table 3 shows the correlations between quality of life and marital relationship.

Life Quality	Marital relationship
Social relations	0.372***
Environment	0.350***

Table 3. Relationship between marital relationship and quality of life.

Note = *** $p < 0.001$.

As shown in Table 3, the higher the level of satisfaction with quality of life at social levels (which evaluated marital and interpersonal relationships) and the environment (which evaluated aspects of satisfaction with leisure, transportation or even housing, among others), the better the marital relationship between fathers and mothers. In fact, in both factors related to quality of life, there are aspects that are directly involved in the marital relationship. Fathers and mothers with good marital relationships are expected to be able to establish better social relationships, since they tend to have a better circle of friendships. In addition, environmental aspects also improve the marital relationship, or not disrupt the relationship.

In this sense, according to Norgren, Souza, Kaslow, Hammerschmidt and Sharlin (2004), the marital relationship is associated with the quality of life of the spouses and vice versa. Satisfaction in marriage and marital relationship can help avoid conflicts and even marital breakdown. Therefore, it is considered that the quality of a relationship is maintained according to the benefits therein obtained, being these greater than the costs (Buss, 2007).

As the results of this study demonstrate, Norgren et al. (2004) concluded that self-esteem, emotional health, partnership and problem-solving strategies among couples influence the quality of life and good relationship between spouses. That is, the greater the satisfaction between the couple, the better the performance of tasks that lead to a good quality of life (socio-environmental). This factor is important because a good marital relationship can, consequently, influence in the increase of the security and the social adaptation of the children, since they follow the model of the psychological mechanisms of monitoring the satisfaction in the relationship (Norgren et al., 2004).

Table 4 shows the significant relationships between the marital relationship and the family routine (evaluated by the FER).

Marital relationship	Family Environment Resources (FER) – Family gatherings
Expression of affection to the partner	0.191*
Partner expresses affection	0.179*
Communication between the couple	0.186*
Good things that the partner does	0.263**
Family environment resources – family gatherings	-0.302**

Table 4. Relation between the level of marital relationship and family routine.

Note = * $p < 0.05$; ** $p < 0.01$.

As for Table 4, it is noted that the higher the frequency of family meetings, the better the marital relations between the parents, as regards to: expression of affection to the partner, expression of affection by the partner; communication between the couple; good things that the partner does.

It is expected that fathers and mothers who maintain a routine of family gatherings will communicate and interact more frequently, increasing marital satisfaction and closeness between the couple (Norgren et al., 2004). Such a factor is important because the transition

to parenting can cause changes in the couple's identity and transformations in the marital relationship; husband and wife will become father and mother, and the couple will become a family unit (Delmore-Ko, Pancer, Hunsberger, & Pratt, 2000). However, this transition does not always occur in a positive and peaceful way.

This research also confirmed that the greater the resource of the family environment, the less accepted the characteristics of the partner that the spouse does not like. It is important that parents have resources to deal with the negative characteristics of the spouse, as non-positive characteristics of the parents may interfere with the behavior of the children (Costa & Mosmann, 2015).

Table 5 shows the significant correlations between marital relationship and family needs.

Marital relationship	FN Support	FN Others	FN Community	FN Family Life	FN Total Factor
Definition of the partner				-0.243**	
Good things the partner does				-0.247**	
Partner's characteristics that you don't like	0.193*	0.190*		0.342***	0.257**
Marital evaluation	-0.188*	-0.223*	-0.209*	-0.290**	-0.235**

Table 5. Relationship between the level of marital relationship and family needs (FN)

Note = * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Regarding marital evaluation, the better the spouse's evaluation of the partner (such as good things the partner does, the definition of the partner, and the overall evaluation), the lower the parents' needs for support, community help, family life, other needs and total factor.

Gottman and Silver (2000) point out that the couple, by showing satisfaction with the spouse's attitudes, strengthens the relationship. Possibly, the strengthening of this relationship causes a mutual support within the couple and diminish the needs they have in other social spheres.

Satisfactory aspects with the spouse contribute to a higher quality of marriage, as it promotes greater understanding in the interaction, reducing the possibility of the emergence of the parents' needs in seeking institutional and community help to deal with stressful situations that occur within the family (Sardinha, Falconi, & Ferreira, 2010), which may or may not relate to the child's disability.

Parents of children with disabilities often need support and resources that enable the development of knowledge and skills learned or reinforced, in order to deal with a new reality (Singh et al., 1995; Turnbull & Turnbull, 2001; Anuradha, 2004). If the support between the couple is reciprocal, the family may present a reduction of the needs regarding stressful situations, valuing the development and interaction among all the members.

Table 6 shows the existing significant correlations between marital relationship and satisfaction with social support.

Marital relationship	Social satisfaction
Definition of the partner	0.234 [*]
Expression of affection to the partner	0.193 [*]
Partner expresses affection	0.267 ^{**}
Communication between the couple	0.314 ^{***}
Good things the partner does	0.231 [*]
Partner's characteristics that you don't like	-0.252 ^{**}
Marital Evaluation	0.337 ^{***}

Table 6. Relationship between the level of marital relationship and satisfaction with social support (SSS).

Note = ^{*}p<0.05; ^{**}p<0.01; ^{***}p<0.001.

With regard to the correlation between social support and social relationships, it is observed that the more parents presented characteristics that did not please their spouse, the less social support was available to them. Just as the positive marital relationship (expression of affection, partner's definition, marital relationship, communication between the couple, good things the partner does, and marital evaluation) was positively correlated to the marital relationship.

In fact, the marital relationship can affect the other interpersonal relationships of the parents, that is, more negative marital relationships can interfere in the way parents relate to others, which influences their social support. On the other hand, individuals who value the qualities of the partner, pointing out their positive points, expressing affection and identifying the good things that the spouse does for them, tend to communicate more adequately (Loos & Casemiro, 2010), which helps to seek and solicit support within the family or in the social context.

The quality of social support coupled with good marital relationship are protective factors for child development, as according to Bolsoni-Silva and Marturano (2010a), low levels of social support with a high incidence of environmental stressors constitute a condition of family vulnerability. Thus, it is clear that, in cases where adverse life events coexist as well as an overloaded marital relationship, there may be reduction or absence of internal support (between family members) or external (social, community) support to cope with problems.

Still in this sense, to Guralnick (1998), the relationship that the parents establish between themselves and with the child, such as affection, attention and constant care, is of great importance and may be related to the source of social support, resources available, social and family support network, etc.

4 FINAL CONSIDERATIONS

This study sought to correlate the marital relationship, needs, quality of life, resources and social support, of fathers and mothers of children with intellectual disability, physical disability, autism and delayed child development.

The results showed that the more harmonious the marital relationship between the couples, the better the resources they obtained in their family environment, the more frequent the family gatherings were, the less the parents had need for support, community help, family life, other needs and total factor, and the highest the level of satisfaction with the quality of social life and the environment.

With regard to the correlation between social support and marital relationship, it is noted that the more parents presented characteristics that did not please their spouse, the less social supports were available to them. Such data provide subsidies for intervention with families of children with disabilities, in order to focus on themes that consider the particular needs of fathers and mothers and the different disabilities that children have.

The data presented in this study became important as it was considered a sample of fathers and mothers of children with different disabilities and delayed neuropsychomotor development, besides investigating a range of variables in the family context. Through this study, it is possible to point out indicatives of interventions and actions in terms of public policies that can be directed to the relatives of children with disabilities and not only to mothers, as is the case with most studies investigating families of children with disability.

Research with higher numbers in each group may help counteract or confirm this study data, in addition to generalizing the results of this research. Studies that compare the variables of parents of children with disabilities with parents of children without disabilities may also help in the amplification or confirmation of data from this research.

It is believed that this study can contribute to the knowledge about the family institution, which is little considered in public policies and social projects, that persist in assistencialism and do not perceive the family as a unit. It is important to provide services, projects and programs that involve families and consider their demands. However, there is a need for more involvement of the fathers in intervention programs, since mothers, as the main caregivers, become the most researched population in studies involving the family.

Therefore, studies involving families of children with disabilities should not be limited to evaluating only the physical and emotional aspects of the parents, but also extended to the support and the tangible support that they can receive. However, to work with families, it is necessary to get to know them and understand their importance for their development, as well as the importance that each parent has in child development and in the performance of their parental roles.

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