ANALYSIS OF THE RELATIONSHIP BETWEEN EARLY INTERVENTION AND FAMILY QUALITY OF LIFE[1]

ANÁLISE DAS RELAÇÕES ENTRE INTERVENÇÃO PRECOCE E QUALIDADE DE VIDA FAMILIAR

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ABSTRACT: Due to the importance of family participation in early intervention programs, research has studied the theme of family quality of life in order to improve early childhood care. The objective of this paper was, therefore, to relate the forms of family organization for the early intervention process with the quality of family life, from the perspective of a family member. It is a qualitative and quantitative research, which used two instruments: the semi-structured interview and the Family Quality of Life Scale (FQOLS). Ten family members of ten children from zero to three years old with potential or already present developmental alterations attended at the Specialized Center for Rehabilitation II of a municipality in the Metropolitan Region of *Baixada Santista*, state of São Paulo, Brazil, participated in the study. It was found that the FQOLS score is similar to other studies, with greater satisfaction in support related to disability and less satisfaction with emotional well-being, in addition to the relationship between the presence of support networks and the quality of family life. It was observed the predominance of fragmented actions between services, the low school attendance of children and the exclusive participation of female family members; obstacles related to the feeling of overload and lack of support were also highlighted.

KEYWORDS: Family. Quality of life. Early childhood.

RESUMO: Devido à importância da participação familiar nos programas de intervenção precoce, pesquisas têm estudado o tema da qualidade de vida familiar a fim de aprimorar o cuidado na primeira infância. O objetivo deste artigo foi, assim, relacionar as formas de organização das famílias para o processo de intervenção precoce com a qualidade de vida familiar, a partir do olhar de um familiar. É uma pesquisa quali-quantitativa, que utilizou dois instrumentos: a entrevista semiestruturada e a Escala de Qualidade de Vida Familiar (EQVF). Participaram do estudo dez familiares de dez crianças de zero a três anos com possíveis ou já presentes alterações do desenvolvimento atendidas no Centro Especializado em Reabilitação II - Deficiência Física e Intelectual (CER-II), de um município da Região Metropolitana da Baixada Santista. Verificou-se que a pontuação da EQVF se aproxima de outras pesquisas, com maior satisfação ao apoio relacionado à deficiência e menor satisfação com o bem-estar emocional, além da relação entre a presença de redes de apoio e a qualidade de vida familiar. Observou-se a predominância de ações fragmentadas entre os serviços, a baixa frequência escolar das crianças e a unanimidade de participação de familiares do gênero feminino; foram, também, ressaltados os obstáculos relacionados à sensação de sobrecarga e à falta de suporte.

PALAVRAS-CHAVE: Família. Qualidade de vida. Primeira infância.

1 INTRODUCTION

The first years of life are crucial for the child's cognitive, affective and emotional development. In this fundamental stage for human development, early childhood, from 0

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to 6 years old, it has been emphasized that the provision of favorable conditions for child development is more effective and less expensive than seeking to reverse or mitigate posteriorly the effects of early adversity (Shonkoff, 2016).

Early Childhood Intervention (ECI) has been considered an important action aimed at the early years of children with a disability, developmental delays or exposed to risk factors. The first justifications that supported early intervention programs were their potential to reduce the effects of a disability or risk factor and promote improvement in development over time (Dunst, 2002).

The evolution of ECI practices was based on the conceptual model of human development that considers it a process of social construction through interaction with others and with the environment, being the family environment central in the children's relationship network. In this perspective, Bronfenbrenner (1996) described the Bioecological Model of Human Development, understanding it in its relationship with the different contexts in which the individual lives. Based on this model, human development occurs through the active participation of individuals, guided and influenced by the relationships with the different systems that surround it, its particularities, as well as its dynamic and changing properties. For this, development happens through proximal processes, through reciprocal and lasting interactions, increasingly complex, between an evolving individual and the people, objects and symbols of the environment, their context and their time (Bronfenbrenner, 1996).

Based on this theoretical framework, there is a process of changing the early intervention model focused on children's deficits to a broader perspective, in order to emphasize the role of the family and the support networks in promoting child development (Carvalho et al., 2016; Dunst, 2002). Thus, when considering the relevance of the various factors that interact with the child's development, this approach includes more instruments for the practice of early intervention, highlighting the importance of attention also directed to these contexts, such as the community, the family and availability of resources.

From this conception, the early intervention approach centered on the family considers the multiple environmental and social variables associated with child development, placing the family at the center of actions that are oriented towards the promotion of family skills and access to the resources and support needed to the exercise of its role and its strengthening (Carvalho et al., 2016). In this perspective, Carl Dunst brings decisive theoretical contributions that include the service network and formal and informal support practices centered on families (Dunst, 2002).

According to this understanding, with great recognition of progress in services in countries such as the United States of America and Portugal, ECI can be defined as a set of actions aimed not only at children with developmental delay or at risk, but also at families and other systems, in order to conceive the family context as the main environment for development, value their skills and respect their choices (Carvalho et al., 2016). More than that, ECI must respond to the needs of the individuals involved and create opportunities to encourage children's development based on individualized and flexible practices guided in family priorities, in order to provide opportunities and resources for their active involvement in collaboration with the professionals (Serrano, 2007).

In the current scenario, early intervention practices centered on the family have been gaining strength and, among its results, the advances in the interaction between children and family members, in well-being and family satisfaction, as well as in co-responsibility among all involved (Carvalho et al., 2016). Its importance has been demonstrated in international research, but still with few studies in Brazil (Marini, Lourenço, & Della Barba, 2017).

Given the progressive appreciation of the family context in child development and its role in health care, the quality of family life has been configured as one of the objectives of early intervention (González, Centeno, Rueda, García, & Peral, 2015). Schalock and Verdugo (2002) emphasize that the concept seeks to address the relationship between daily needs and demands with the family's possibilities to face them, perceiving the quality of family life in a unique, multifactorial way and with the impact of other ecological systems in that process. In addition to satisfying needs, the quality of family life considers the family's potential, its self-confidence and its empowerment, besides the support provided by the environment, services and support networks.

This is so because, in addition to the objective aspects, the quality of family life encompasses the individual's subjective perception of his/her experiences, configuring as a possibility of understanding this dynamic in the lives of its members, especially when one of them has some developmental delay or disability. This specifies the potential and the needs of this context in order to guide the intervention linked to the social environment and natural support (González et al., 2015). Thus, when considering the expanded conception of development in its relationship with different contexts, as well as the increased appreciation of the family role in health interventions, the past decades have revealed a significant increase in interest about research on family quality of life (Ferreira, 2014; González et al., 2015).

Given the above, this study aimed to relate the forms of family organization for the early intervention process with the quality of family life, from the perspective of a family member.

2 Method

The methodological approach was qualitative and quantitative, and the context of the research refers to the Specialized Center for Rehabilitation II - Physical and Intellectual Disability (SCR-II), a rehabilitation service of the Municipal Health Department of a municipality in the Metropolitan Region of *Baixada Santista*, located in the state of São Paulo, Brazil. SCR-II, according to the Care Network for Persons with Disabilities (Ordinance no. 793, of April 24, 2012), is an outpatient clinic specialized in rehabilitation that performs diagnosis and treatment of physical and intellectual disabilities, considering the need to start rehabilitation and prevention actions early, becoming a reference for the health care network in the territory.

2.1 Participants

This research used a non-probabilistic sample for convenience, in which participants were selected according to accessibility (Oliveira, 2001), considering the following criteria: family members of children attended at the SCR-II unit of a municipality in the Metropolitan Region of

Baixada Santista, family members of children from zero to three years old with possible or already present developmental changes, being enrolled and attending the service in 2017.

Based on access to the service's medical records, twenty-one children with these characteristics were identified. Of these, ten children were referred by reference therapists and their families were invited to participate in the research. We included those who, after clarifying the objectives of the study, agreed to participate and signed the Informed Consent Form (ICF).

Therefore, this study had as participants ten family members of ten children from zero to three years old with possible or already present developmental changes attended at a SCR-II unit in the city, enrolled in the service in 2017.

2.2 INSTRUMENTS

As one of the research instruments, a semi-structured interview was used based on a script developed around the research objectives, starting from main topics complemented by other questions that could arise at the time of the interview. Thus, the interview script was based on guiding questions and addressed the child's history and family environment, the family's conceptions about their role in the child's development, the paths taken to seek support, the barriers they encounter, as well as the way they perceive their quality of life. There was the possibility of opening new questions and clarifying the information obtained, and free comments were also collected that eventually emerged on the topics.

The other instrument used was the Family Quality of Life Scale (FQOLS), culturally adapted to Brazilian Portuguese, by Jorge, Levy and Granato (2015). The scale was created and standardized from a project in the United States of America with the aim of assessing the quality of life in families that have children with pathologies in general. The scale consists of 25 items divided into five domains, namely: family interaction, parent-child relationship, emotional well-being, physical/material well-being and support related to disability. It has five types of responses for satisfaction, evaluated on a Likert scale, one for very dissatisfied, two for dissatisfied, three for neither satisfied nor dissatisfied, four for satisfied and five for very satisfied (Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Jorge, Levy, & Granato, 2015).

2.3 PROCEDURES

This study was carried out in accordance with Resolution no. 466, of December 12, 2012, having been submitted to the Ethics and Research Committee of the Municipal Health Secretariat and to the Ethics Committee in Research with Human Beings at the Federal University of São Paulo (UNIFESP), having been approved under Opinion no. 2,332,058.

Family members were invited, either in person or by telephone, to participate in the study on a voluntary basis and interviews were scheduled. On the date and time defined, before the interview and the completion of the scale, the objectives of the research were clarified, the doubts presented and the participants signed the ICF.

Semi-structured interviews were conducted followed by filling out the FQOLS with ten family members of ten children, in search of listening to their narratives between November

2017 and March 2018. These were conducted individually in a single meeting in the SCR-II service room and recorded as accepted by the participants for later transcription.

2.4 DATA ANALYSIS

The data collected by completing the FQOLS were accounted for and, with the support of a statistician, analyzed using descriptive statistics that make it possible to "describe and evaluate a certain group, without drawing any conclusions or inferences about a larger group" (Peternelli, 2006, p. 13). To investigate the association between the FQOLS domains, as well as the FQOLS with the variables of total family income and number of children, Pearson's linear correlation coefficient was used. In addition, to compare the FQOLS domains in relation to the family variables "being employed" and "child being at school", Student's t-test was used for unrelated samples, with a statistical difference of $p \leq 0.05$ being used.

The data obtained from the semi-structured interview were analyzed according to the perspective of thematic content analysis. According to her, "the theme is the unity of meaning that is naturally freed from a text analyzed according to criteria related to the theory that serves as a guide to reading" (Bardin, 1979, p. 105). Thus, the trajectory of data analysis must go through the stages of pre-analysis, exploration of the material and treatment of the results obtained/interpretation, with the speeches being classified according to thematic categories in an attempt to identify the broader meanings attributed to them. Then, the themes emerged were articulated with the research objectives and discussed based on the theoretical framework.

3 RESULTS

For the presentation of results, the names of family members who participated in the study were replaced by the codes Family 1 to Family 10, as well as the names of children, professionals and other people mentioned in the interviews were changed to fictitious names in order to preserve the secrecy. Regarding the characterization of the participants (Table I), the ten family members who agreed to participate in the research were female (100%) aged between 21 and 38 years old, with an average age of 28.4 years old. The ten participants were mothers of the children attended and they were between 3 and 35 months old, with an average of 16.7 months.

The family nucleus consisted of an average of 3.9 members, with three being the minimum number and six the maximum number of members in the family. The number of children varied between one and four, with an average of 1.9. The total family income was between R$340.00 and $ 3,700.00 with an average of R$ 1,772.00, but a family member was unable to inform. In addition, among family members, 60% of respondents work and 70% of children are not enrolled in a school unit.

Family	Family member age	Number of children	Number of family members	Total family income *	Family member interviewed is employed	Child's age	Child attends school
Family member 1	32 years old	1	3	R$ 2.000	Yes	35 months old	Yes
Family member 2	38 years old	3	5	R$ 2.000	Yes	4 months old	No
Family member 3	22 years old	1	3	R$ 954	Yes	31 months old	Yes

Family member 4	33 years old	4	6	not informed	No	25 months old	No
Family member 5	30 years old	2	4	R$ 2.000	Yes	32 months old	Yes
Family member 6	25 years old	2	4	R$ 3.700	Yes	4 months old	No
Family member 7	33 years old	1	4	R$ 2.000	Yes	3 months old	No
Family member 8	25 years old	3	4	R$ 340	No	7 months old	No
Family member 9	21 years old	1	3	R$ 2.000	No	7 months old	No
Family member 10	25 years old	1	3	R$ 954	No	19 months old	No

Table 1. Characterization of family members according to age, family composition, total family income, insertion of the family member in the labor market, child's age and school attendance.
Source: Elaborated by the authors.
* Note: The minimum wage at the time of data collection was R$ 937.00 (Decree No. 8,948, of December 29, 2016).

From the FQOLS (Table 2), it is possible to point out the average score of quality of family life of the participants of 3.83, with a minimum value of 3.01 and a maximum of 4.41. Among the domains evaluated, the average of the item *family interaction* reached 3.91, the item *parent-child relationship* obtained an average of 4.11, the item *emotional well-being* was 2.95 points average, the item *physical and material well-being* scored an average of 3.70 and, finally, the item *support related to disability* reached an average of 4.52. As it can be seen, *support related to disability* is the domain that presents the highest degree of satisfaction (average = 4.52), while the domain of *emotional well-being* obtained less satisfaction by family members (average = 2.95).

Family	**Family Interaction**	**Relationship between parents and children**	**Emotional well-being**	**Physical and material well-being**	**Disability -related support**	**Total**
Family member 1	3,16	4,50	3,50	3,60	4,50	3,85
Family member 2	4,83	4,66	3,50	4,60	4,50	4,41
Family member 3	4,50	4,33	3,75	4,20	5,00	4,35
Family member 4	2,33	3,50	2,00	3,00	4,25	3,01
Family member 5	4,33	4,66	3,25	4,40	4,75	4,27
Family member 6	4,00	3,66	2,75	4,20	4,50	3,82
Family member 7	4,50	4,66	3,75	3,40	5,00	4,26
Family member 8	3,00	3,50	2,00	3,80	4,25	3,31
Family member 9	4,50	4,33	2,75	3,20	4,75	3,90
Family member 10	4,16	3,66	2,25	2,60	3,75	3,28

Table 2. Average of domains of family quality of life.
Source: Elaborated by the authors.

Regarding the association between the FQOLS domains, there were no strong correlations between them, as well as the FQOLS with the variables total family income and number of children. However, the results obtained allow us to say that there was a difference between the families in which the interviewed relative works and in those in which the relative is not employed for the variables parent-child relationship (p = 0.036), emotional well-being (p = 0.001), physical and material well-being (p = 0.025) and the total Family Quality of Life (p = 0.020). It was also possible to state that there was a difference between the families where the child is at school and the families where the children do not attend for the variable emotional well-being (p = 0.031).

From the analysis of the interviews, three thematic categories emerged: *early intervention: care paths and practices; family environment and configurations; quality of life: definitions and expectations.*

- *Early Intervention: care paths and practices*

This thematic category emerged from the family reports related to the paths taken by them for early intervention, the organization and the roles of the services in this path, in addition to the possible formal and informal support networks. The path taken by families between health and education services with little network articulation was highlighted, predominantly based on requests for exams and referrals from a professional to a more specialized one.

> *Then he asked to take the x-ray to see if it had fractured. Only it took two x-rays and it wasn't fractured. Then he said: "this is not my case". Because he doesn't take care of it, he works with Physiotherapy, it is ... more with a broken arm, with plaster, these things. He said: "look, I'm going to send you to Santa Casa Hospital, to the Santa Casa's specialists.* (Family member 2).
> *She sent me there, then I went to Santa Casa. When I went to Santa Casa, the orthopedist said: "yes, he really has congenital torticollis and he is going to do physiotherapy" [...], but I said: "where is the physiotherapy?". Then he said: "he has to go to the polyclinic because there isn't here".* (Family member 7).

The school context appears to play an important role in this path; however, conceptions about the school context and the need for adaptation are placed as barriers in everyday life.

> *Because I put him in school, I had, right? And ... what happens, I noticed that he was coming back very dejected, right? And I talked to them, I told them about Samuel, what he was like, and they told me that they couldn't give him any special care because he didn't have the medical report. (…). And I want to put him in school because it's good for him. It really is good, right?.* (Family member 10).
> *It is not with anyone that I can leave her and she doesn't ... sometimes I think about letting her go to daycare, but, on the other hand, I get scared, right? Because the other children ... she already has a delay, the other children are so much smarter, more developed than she is, then I'm afraid of them hitting her, something. And there is a doctor every week, she will always be absent and will stay ... how do you say? Until she gets used to it and when she thinks she's getting used to it, she has to go to the doctor, right?.* (Family member 8).
> *I tried, but as she has a very regular diet, she is allergic to milk protein, so nothing that contains milk she can eat [...], that's what they said at the nursery.* (Family member 9).

It was also possible to identify the difficulties encountered by family members such as the organization of routine and reconciliation with other tasks and commitments. In this sense, support networks, formal as the health unit and informal as relationships with family members, friends and acquaintances, appeared in the family members' speech as a possibility of support and resilience, in order to demonstrate their potency in the forms of organization of families for insertion in the early intervention service, engagement in care, as well as facing the difficulties encountered along this path.

> *Then one helped the other at home ... my mother too. And so he gradually developed, right? He developed little by little and he was ... But now he has improved a lot after he started to come here. [...]. In this part, you helped my son a lot ... and me too, right?.* (Family member 1).
> *Then he started missing classes a lot, I almost lost my seat here because of that, right? Because he was absent, my husband would bring him, then he wouldn't bring him and then one week he would come, then he wouldn't come for two weeks ... and for a moment he would lose it. That was when this friend of mine appeared. [...] and she started to help me bring him.* (Family member 3).

- *Familiar environments and settings*

In this thematic category, there are forms of family organization and perceptions about the family roles played in this context. It is noted that the family is understood as the context closest to the child, emphasizing its importance in monitoring child development and as support in the face of difficulties. However, in some cases, the family has its role placed as an intermediary between the services provided and the development of the children, with its participation not being centrally and actively involved in health care.

> *Ah ... I think I helped a lot, right? With your help, right? It was even better then, you know? I ... so, as I talked to you, I tried to do it at home, you know? And so he was developing more.* (Family member 1).
> *My role? I think it's important, right? Because I am the person who is closest to her, so I have to be on her side, I have to help her, do the homework they ask here too*. (Family member 6).

In these settings, it is highlighted the role of the mother as the main caregiver, responsible for the development and monitoring of the child, generating a feeling of weariness and overload. In this sense, although the influence of the structure of the family environment and socioeconomic conditions on the difficulties perceived by the families is pointed out, the main obstacles narrated go beyond the children's health condition and the material conditions of the family, but they highlight the perceived overload, the need to reconcile various tasks and the lack of support to face this situation.

> *So, it's all me, right? Her father is working now, we have no family close by, his mother is elderly, my mother is already deceased, so there is not much help. It's me.* (Family member 6).
> *Lack of help. At least once he goes to a meeting ... even to bring him here. It's okay that he works, you know? But he has an autonomous job, he is a street vendor, if he wanted to help, attend one of the meetings, it would help. Even to wash the dishes, it would help a lot.* (Family member 4).

- *Quality of life: definitions and expectations*

It highlighted the meaning attributed by family members to their quality of life, their experiences, their relationships, their potential and their difficulties experienced on this path.

Although, at times, a single aspect is highlighted, such as the children's well-being, the family's financial and health condition, the quality of life is mostly indicated in a multidimensional way, linked to the subjective perception of the lived experiences. In this sense, the dynamics of family relationships, the presence of support networks, opportunities for access to services and the possibility of satisfying needs and desires are highlighted.

> *At home, being able to get attention. This I often think is lost in families, right? Regardless of money ... in a good family, I think love. [...]. So, if we have it, we can do anything, right?.* (Family member 3).
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> *For me, no quality of life. [...]. When it comes to having a big family, there is no dialogue, no help at all, you know? I live in a shack, but I have a brother, two, three who live in a house, who live in a two-story house, who have a car, have a motorcycle, do you understand? They will never ask if you need a diaper, a liter of milk, you are on your own.* (Family member 4).

4 DISCUSSION

In the results, it can be noticed that the path taken by the families happens, in great part, in a disarticulated way through the filling of referral forms directed to specialized services, with little space for discussion and exchange among professionals. In addition, what is perceived in this practice is that there is a lack of dialogue with family members, with little space for listening and appreciation. This data is in line with other studies that reveal unilateral organized care, with family members placed in a passive position and with difficulties to find space in this dynamic (Hove et al., 2009). However, when considering the child's globality in an integral and contextualized way, the networking, which includes the family role, is central to interconnecting different sectors and resources that cross the complexity of child development (Almeida, 2004).

When considering the bioecological perspective, in which the constant relationship between systems causes interference at all levels, the organization of public policies has a fundamental role in the practice of care by emphasizing the importance of networking and the integrality of actions (HumanizaSUS, 2004; National Plan for Early Childhood, 2010). However, the direction towards services and specialists, seen in professional practices, still seems to carry a fragmented conception of health as a backdrop, going against the need for a comprehensive understanding of the subject and their contexts, devaluing the reports and the difficulties faced by individuals and their families. In this sense, the results found in this study can be compared with those obtained by Costa, Jorge, Vasconcelos, Paula and Bezerra (2014) when stating that the practice based on referrals can generate consequences for the integrality of health care.

Primary care services appear as the first point of this care network, but with a role mainly related to the detection of risk signs pointed out by the doctor and referrals. It is worth highlighting the potential of these points in the network to act more broadly, aiming at the continuity of monitoring the development of children and acting with families, promoting spaces for reception, support and guidance, in addition to acting in the promotion of intersectoral actions integrated (Early Stimulation Guidelines, 2016). The good experiences pointed out by the family members are related to the perception of support, the listening and attention received in the services, as well as the possibilities of dialogue with professionals. For this to occur, it is necessary to create paths for an active partnership between professionals and family members, considering the complexity of the individual and their contexts (Carvalho et al., 2016).

In addition to the gateway to the health network, the school context plays an important role in the path to care at the ECI. According to Bronfenbrenner (1996), the school has a fundamental role in promoting child development, since the insertion of the child in a new microsystem allows different relationships and experiences, enabling support for the child and promoting interaction between contexts. Although the potential of relationships established at school and its importance in family support is highlighted by family members, the need for adaptation and fears regarding the child's insertion in the educational context are presented as major challenges.

These difficulties appear in school attendance, since it can be seen in the results of the characterization of the participants that 70% of the children are not enrolled in a teaching unit, proving to be even greater than that indicated by the 2015 School Census, in which 48.05% of all children in the municipality between zero and three years old, with and without developmental changes, were not enrolled in the daycare center (Fundação Seade, 2016).

Low school attendance goes against what is proposed by family-centered practices that understand the school, in addition to the family environment, as a natural context in the inclusion of children with some special need by providing opportunities for social interaction and independence through everyday situations (Carvalho et al., 2016). In addition, it shows us that, although school inclusion has its importance constantly discussed, it is still necessary to rethink the contours of this institution, which is often faced with the lack of basic aspects to guarantee the insertion and continuity of these students in school, evidenced by the contradictions of the policies linked to the theme in the early childhood age group, which still little highlights the place of disability in education (Silva, 2017).

Besides, another aspect pointed out as a challenge in the path to early intervention refers to the particular conditions of access to services and the possibilities of structural and routine organization of the family. According to Oliveira (2016), in his study of legal norms about early childhood in Brazil, public policies describe the idea of a universal childhood in which everyone has the same rights, without problematizing the different conditions that each individual and their families find access to them. In this way, the singularities of each context are lost, making it necessary to approach the different forms of family organization, also considering the relations with the broader issues of the other systems - meso, exo and macrosystem - in order to encompass everyone and guarantee comprehensive care and attention.

In this sense, among the predominant forms of organization in the results, there is the unanimous participation of female family members identified as mothers of children, which leads us to consider the role of this function within the family context and in the health care process. The main caregiver's gender has been verified in studies on family quality of life of people with disabilities, and the female gender still constitutes the majority of family caregivers, deserving special attention since there is a greater accumulation of care tasks and are more limited in social activities (Balcells-Balcells, Giné, Guàrdia-Olmos, Summers, & Mas, 2019; Ferreira, 2014; González et al., 2015; Jackson, Wegner, & Turnbull, 2010; Jorge, 2011; Summers et at., 2007). This context can be seen in the data presented on mothers' participation, even though most of them are employed. Despite the contemporary changes related to the family constitution, this fact is in line with the macrosystemic conception that the care of domestic tasks is still associated with the female role, and the attention to the development of children remains linked to the relationship between mother and child, despite the growing participation of women in the labor market (Borsa & Nunes, 2011).

Among the forms of organization of the family context, although the family members mention the material and structural difficulties, in the FQOLS, the item material well-being is not the one with the lowest satisfaction score. Like other studies carried out with the FQOLS, with families of children with disabilities, they have also not shown the lowest scores in this domain, both in the international scenario (Balcells-Balcells et al., 2019; Ferreira, 2014; Jackson et al., 2010; Summers et al., 2007) as in the Brazilian reality (Jorge, 2011). On the one hand, this data corroborates the findings of other studies conducted with families of children with disabilities in Brazil that have found that the difficulties faced in this context go beyond family income (Jorge, 2011). On the other hand, some international studies show a relationship between the low values of the domain material well-being and the low income situation faced by families (Jackson et al., 2010), as well as between material well-being and family interaction (Ferreira, 2014).

The average quality of family life of the participants indicated by the FQOLS is 3.83, a value that is close to that indicated by other surveys with the same instrument, such as those carried out in Australia and Belgium, which observed the values of 3.8 and 3.9 respectively (Brown, 2008). In relation to the United States, the result presented here is among the values found in two surveys carried out in that country that showed an average of 3.99 (Summers et al., 2007) and 3.66 (Balcells-Balcells et al., 2019). In reference to studies carried out in other countries (Brown, 2008), the values obtained here are slightly higher than the averages observed in Japan (3.2), Slovenia (3.4), Canada (3.5), Israel (3.5) and Nigeria (3.6). In Portugal, Ferreira (2014) found an average of 4.12, a value above that described in the present study, concluding that this result demonstrated families' satisfaction with their Quality of Family Life.

Among the domains of the FQOLS, it can be seen that emotional well-being obtained less satisfaction by family members. In another study carried out in the country (Jorge, 2011), emotional well-being also obtained the lowest score by family members, as it has also been described in international studies (Balcells-Balcells et al., 2019; Ferreira, 2014; Jackson et al., 2010; Summers et al., 2007). Unlike other studies that showed greater satisfaction with physical and material well-being (Summers et al., 2007), with the relationship of parents with their children (Balcells-Balcells et al., 2019) and with family interaction (Jorge, 2011; Ferreira, 2014), this study shows the greatest satisfaction with support related to disability. It can be understood that, while support related to disability portrays the perception of support for children in their daily lives, whether at school, in the health unit or at home, emotional well-being is related to support for family members, including the possibility of satisfying their personal interests and the presence of external assistance.

This discrepancy in the perception of the support received for the child and the family member can interfere with the participation of caregivers in the child's care and activities, which points to the need for actions and support aimed at the family context, given the importance of these relationships in child development. According to the family-centered approach, early intervention actions must take as one of their main objectives the recognition of family needs and priorities, focusing their practices on promoting opportunities for access to resources and support for family members (Serrano, 2007).

In this sense, it is possible to observe that, in addition to the objective or material aspects, the family members emphasize the quality of family life in its subjective component, emphasizing the perception of their experiences, the relationships established, the challenge of accessing resources and reconciling different tasks, in addition to the lack of support to face this situation. To Poletto and Koller (2008), according to the bioecological framework, the constitution and organization of the family context goes beyond just its structure, but it is influenced by the quality of relationships and interactions with all systems. To corroborate, Mioto and Prá (2015) emphasize that the well-being of individuals depends not only on material conditions, but on the possibilities of organization and access to resources that are available in that context.

Thus, the networks of family relationships in their varied contexts can act as support in the face of these difficulties. For Bronfenbrenner (1996), the so-called social support networks appear in the interconnection between environments and offer social, material, informative and affective support, being among the most relevant exosystems for child development, in view of their importance for the family context. Networks, formal or informal, cross the environments and can involve family members, friends, neighbors, professionals, among others (Poletto & Koller, 2008), with the main function of providing resources to meet the needs of individuals and their families, in order to complement their capabilities and possibilities (Serrano, 2007).

In family reports, the health unit, school and work are highlighted as important points in this support network, in addition to friends, family members and other acquaintances. Likewise, in the results described by the FQOLS, it is possible to observe the importance of some of these points in the network in the quality of family life, with a difference in the scale domains being pointed out between the families where the child attends and does not attend school, as well as between the families that the interviewed relative works and those where the relative is not employed.

With regard to job insertion, Jorge (2011) also found a positive relationship between the family member being employed and the quality of family life, as well as other studies that indicate an increased feeling of burden when related to the mother not being employed (Macedo, Silva, Paiva, & Ramos 2015). Bronfenbrenner (1996) also describes that the parents' work, although it does not actively include the child, is an exosystem with great influence on their development. In relation to the school environment, its strengthening as an ecological system is essential in view of its protective role as a social support network (Poletto & Koller, 2008). This data points out the need and the challenge of reinforcing this context, including and expanding its performance, considering it as an important point in the support network, in child development and in the quality of family life.

The potential of the health unit as a support network is also described in other studies, pointing out the effectiveness of the results of early intervention in child development, but also in the quality of family life through professional support and information received (Ferreira, 2014). Regarding the network of friends, family and other acquaintances, Serrano (2007) states that these informal networks assist in care and routine, showing a strong relationship with meeting the needs of families, and their positive effects gain evidence in situations of vulnerability, organizing itself as a protective factor in the face of difficulties throughout life.

It is worth considering that studies on quality of life claim that it is significantly expanded when access to the appropriate support and resources is available for each individual and family (Schalock & Verdugo, 2002). In the same sense, social support networks in their various configurations, whether formal or informal, appear in studies of early intervention centered on the family, positively relating their presence to the child's development, forms of organization and family well-being, it is important to understand them for the planning and structuring of services (Dunst, 2002; Serrano, 2007).

However, although this network is configured as one of the goals of early family-centered intervention (Balcells-Balcells et al., 2019), it depends on the availability of the interactions of the exosystem, that is, the services provided and community factors in providing support for the needs of the child and his/her family (Serrano, 2007). From this perspective, it is understood that the quality of family life is related to the availability of adequate resources for well-being, but also to the empowerment of family members in this access, increasing the opportunities for access and their role in achieving a life of quality (Ferreira, 2014; Shaclock & Verdugo, 2002).

However, it can be seen that the current way of organizing early intervention in Brazil is still limited, since it little emphasizes and gives space to other sources of support other than professional or formal, leaving community and social resources out of reach. Bearing in mind that these resources, so valued by the family-centered approach and the perspective of the quality of family life, are capable of providing opportunities and promoting positive impacts on the needs of the child and his/her family, early intervention should seek to mobilize the resources of the community and provide forms of support that enable opportunities for the development of children and their families, enabling this access through coordinated and respectful partnership actions with all those involved. For that, it is necessary that health practices consider the central role of families in child development in an active and individualized way, taking into account the forms of organization of the individual's life, their expectations and the possibilities in which they find themselves, being inclusion of the quality of family life in the debate and in the actions of early intervention, a possible path for more amplified and contextualized practices.

5 Final considerations

This paper aimed to relate the forms of family organization for the early intervention process with the quality of family life. In the paths taken in the early intervention, primary care services and the school context appear to play an important role, however it is possible to visualize the low school attendance of children monitored in the early intervention. It is noted that families are faced with the great appreciation of professional knowledge and with fragmented actions among most services, with little space for discussion among professionals, networking and valuing family knowledge.

It was also possible to observe the unanimous participation of female family members, despite the participation of women in the labor market. In addition, family members' scores on the Family Quality of Life Scale are close to those described by other studies, with greater satisfaction in support related to disability and less satisfaction with emotional well-being, in addition to the relationship between the presence of networks support and quality of family life. In this sense, although the objective and structural difficulties related to these forms of organization are pointed out, the family members of this study emphasize the obstacles faced beyond these characteristics, emphasizing the relationships established and the challenge of reconciling the different tasks, generating consequences on the quality of family life. Thus, the results allowed to identify that the presence of support networks appears linked to the relief of the feeling of overload and satisfaction with the family's quality of life.

Thus, it is concluded that reinforcing and mobilizing the resources of the support networks, formal or informal, is fundamental for strengthening the quality of family life since benefits are described in this factor when there is an active participation of individuals and appropriate support is available in the environments. In addition, there is the potency of family-centered practices that precisely propose to act in the empowerment of those involved and in this promotion of access to support networks, resources and services. Finally, it is understood that the encouragement of public policies and practices of early intervention centered on the family that place the quality of family life among the fundamental objectives of their actions can be a way to expand the services provided and supply comprehensive care to children and their families.

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