SEVERE OR PROFOUND INTELLECTUAL DISABILITY: A QUALITATIVE INVESTIGATION OF MATERNAL COPING STRATEGIES[1]

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ABSTRACT. The objective was to investigate coping strategies reported by a sample of Brazilian mothers of children with severe or profound intellectual disabilities. The few Brazilian studies on this object justified the present qualitative exploration of the theme. Fifteen mothers participated, recruited by convenience in health services from a municipality in the interior of the state of São Paulo, Brazil. Individual semi-structured interviews and a thematic content analysis were carried out. The results comprise fifteen themes, induced directly from the corpus; they were allocated into three pre-categories based on theoretical studies on coping. Predominant mentions of coping strategies concerned those centered on problem and interpersonal relationships, which were mixed with strategies focused on emotion. Our interviewees did not seem to consider themselves targets of policies that induce a comprehensive care for people with disability in the Brazilian Unified Health System, in force for about two decades, and whose effective implementation could help extrapolate care based predominantly, on parental responsibility in the views of the participants. They expressed demands for a greater effectiveness also from the sectors of social service, education and transport. They pointed out the need for greater social interaction and socio-community support, seeming to express expectations of a progressive cultural redesign of an ethics of care that fosters actions in the extra-family sphere, reducing their overloads. These aspects of the interviewees' statements can be addressed in the clinical management of their children. A progressively healthier coping with the condition they are experiencing would also benefit individuals with disabilities.

Keywords: Intellectual disability; coping strategies; psychological adaptation.

DEFICIÊNCIA INTELECTUAL GRAVE OU PROFUNDA: INVESTIGAÇÃO QUALITATIVA DE ESTRATÉGIAS MATERNAS DE ENFRENTAMENTO

RESUMO. Objetivou-se investigar estratégias de enfrentamento relatadas por uma amostra de mães brasileiras de filhos com deficiência intelectual grave ou profunda. Os

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poucos estudos brasileiros sobre este objeto justificaram a exploração qualitativa do tema. Participaram quinze mães recrutadas por conveniência em serviços de saúde de um município do Estado de São Paulo, Brasil. Foram feitas entrevistas semiestruturadas individuais e uma análise temática de conteúdo. Os resultados compreendem quinze temas, induzidos diretamente do *corpus* e alocados em três pré-categorias baseadas em estudos teóricos sobre *coping*. Houve um predomínio de menções a estratégias de enfrentamento centradas no problema e nas relações interpessoais, mescladas com estratégias centradas na emoção. Nossas entrevistadas não pareceram considerar-se alvos das políticas indutoras da atenção integral às pessoas com deficiência do Sistema Único de Saúde brasileiro, vigentes há cerca de duas décadas, e cuja efetiva implementação poderia ajudar a extrapolar o cuidado baseado preponderantemente na responsabilidade parental, em suas visões. Em suas falas, há demandas de maior efetividade também dos setores de serviço social, educação e transporte. Apontaram necessidades de maior interação e apoio sociocomunitário, expressando expectativas de um progressivo redesenho cultural da ética do cuidado que fomente ações no âmbito extrafamiliar, diminuindo suas sobrecargas. Esses aspectos das falas das entrevistadas podem ser abordados no manejo clínico dos filhos. Um enfrentamento progressivamente mais saudável da condição por que passam traria benefícios diretos também aos indivíduos com deficiência.

Palavras-chave: Deficiência intelectual; estratégias de enfrentamento; adaptação psicológica.

DISCAPACIDAD INTELECTUAL GRAVE O PROFUNDA: INVESTIGACIÓN CUALITATIVA DE ESTRATEGIAS DE AFRONTAMIENTO MATERNO

RESUMEN. El objetivo fue investigar las estrategias de afrontamiento reportadas por una muestra de madres brasileñas de niños con discapacidades intelectuales severas o profundas. Los pocos estudios brasileños sobre este objeto justificaron la exploración cualitativa del tema. Quince madres participaron, reclutadas por conveniencia en los servicios de salud de un municipio del estado de São Paulo, Brasil. Se realizaron entrevistas semiestructuradas individuales y un análisis de contenido temático. Los resultados comprenden quince temas, inducidos directamente del corpus; fueron asignados en tres categorías previas teóricamente basadas. Las menciones predominantes de estrategias de afrontamiento se referían a aquellos centrados en problemas y relaciones interpersonales, que se mezclaron con estrategias centradas en la emoción. Nuestras entrevistadas no parecían considerarse objetivos de políticas inductoras de una atención integral para las personas con deficiencia en el Sistema Único de Salud de Brasil, en vigor durante aproximadamente dos décadas, y cuya implementación efectiva podría ayudar a extrapolar la atención basada principalmente sobre responsabilidad parental, en sus opiniones. Expresaron demandas de una mayor efectividad de los sectores de servicio social, educación y transporte. Señalaron la necesidad de una mayor interacción social y apoyo sociocomunitario, y parecían expresar las expectativas de un rediseño cultural progresivo de una ética de la atención que fomente acciones en el ámbito extrafamiliar, reduciendo sus sobrecargas. Estos aspectos de las declaraciones de los entrevistados pueden abordarse en el manejo clínico de sus hijos. Un afrontamiento más saludable de la condición que están experimentando también beneficiaría a las personas con discapacidades.

Introduction

Coping strategies encompass a set of cognitive and behavioral methods used to adapt to stressful events, being characterized as psychological adaptation strategies (Folkman, 1984). The transactional theoretical model of stress and coping, conceived by Lazarus and Folkman (1984), has been widely used to understand coping strategies (Wethington, Glanz, & Schwartz, 2015). In this model, coping is considered as a process of interaction between the individual and the environment: faced with a stressful event, the individual performs an assessment of potential damage or threats, and then makes a so-called secondary assessment of his/her ability to change the situation and manage negative emotional reactions. Adjustment efforts, aimed at problem management and emotional regulation, would give rise to different coping strategies (Wethington et al., 2015).

Coping processes presuppose an individual evaluation capacity involving perception and interpretation of experiences, generating efforts to manage internal and external needs to minimize or tolerate stress. Thus, coping strategies are deliberate and conscious actions that can be learned, used and discarded.

In the transactional model, coping strategies are classified as problem-centered or emotion-centered (Lazarus & Folkman, 1984). The former are focused on external reality, in an attempt to remove or mitigate the stressing source, and are usually used when the stressful event is understood as possible to be controlled (Lazarus & Folkman, 1984; Wethington et al., 2015). Emotion-centered strategies, in general, are composed of processes that aim to reduce unpleasant sensations related to a situation perceived as hostile, mitigating the emotional impact even if there is no modification of the stressor event (Lazarus & Folkman, 1984; Wethington et al., 2015). O'Brien and DeLongis described coping centered on interpersonal relationships, in which the individual seeks support from people with whom they have a social bond (O'Brien & DeLongis, 1996).

The different forms of coping occur dynamically, in the sense that different forms of coping can be used simultaneously and can be modified over time and according to circumstances (Folkman, 1984).

An integrative review on coping strategies used by parents of children with intellectual disabilities identified thirteen articles, none of which were developed in Brazil (Santos & Pereira-Martins, 2016). In this review, the main strategies mentioned were the search for social support from family members and professional services, the union of couple and the search for information. The search for social support seemed to be associated with the strengthening of family resilience. On the other hand, fantasy thinking, self-blame, distancing and social isolation were negatively related to the adaptive capacity of families (Santos & Pereira-Martins, 2016).

Considering that the characterization and understanding of these strategies can be useful in clinical interventions and in planning public health policies, the present study investigated the strategies reported by a sample of Brazilian mothers who have children with severe or profound intellectual disability.

Method

Scenario and study design

This study was conducted in São Carlos, a city located in the state of São Paulo, Brazil, with approximately 230,000 inhabitants.

The exploration of the research object took place using a method called clinical-qualitative (Turato, 2011). This method includes techniques and procedures to describe and understand the meanings given to the health-disease-care process by people involved in this process (professionals and users of the health sector, including patients and family members, people exposed to situations or risk factors for health, etc.). Valuing these people's anguish, the researcher seeks to maintain a clinical attitude of attention to their needs during their investigative undertakings. For this, the investigator should preferably have practical knowledge and clinical experience about the object of study or, at least, be versed in the theoretical principles about it (Turato, 2011), realizing the complexity of the variables and factors involved in clinical activities.

The research project was approved by the Human Research Ethics Committee of the University to which the authors are linked (Opinion 1894911), with all participants signing the approved Informed Consent.

Characteristics of the participants

The sample was selected by convenience, characterized in Chart 1. Participants and their children attended a Medical Genetics outpatient clinic and/or the Association of Parents and Friends of Exceptional Children (APAE) in the municipality. The sampling process sought to form a heterogeneous group of participants in terms of sociodemographic characteristics (of the interviewees) and clinical characteristics (of the children). On the other hand, the sample was homogeneous in terms of origin, attendance at the same health services and the same clinical diagnoses of their children. Some of these children used a wheelchair, representing, in general, additional difficulties in the daily lives of families. There was an intention to specifically include female participants (mothers), since they are, usually, in different cultures, including Brazil, the main caregivers of children with disabilities. In the end, the sample consisted of 15 mothers of patients with severe or profound intellectual disability, diagnosed as such during a previous clinical follow-up. The final number of participants was closed by the criterion of theoretical saturation, that is, when the researchers considered having enough data to correspond to the research objectives and that, to a certain extent, were already repeated in the data collection process (Turato, 2011).

The age of participants ranged from 21 to 63 years. We sought to include participants with verbal expressiveness considered sufficient to support an in-depth interview, reporting their ideas, emotions and values about the experiences of having a child with severe or profound intellectual disability.

Chart 1. Sociodemographic characterization of the investigated sample (N=15).

Characteristic	N (total = 15)	%
Skin color		
White	7	46.7
Black	6	40
Brown	2	13.3
Religion		
Practicing Catholic	3	20
Non-practicing Catholic	5	33.3
Practicing evangelical	6	40
Practicing Jehovah's Witness	1	6.7
Marital status		
Married	11	73.3
Single	3	20
Widow	1	6.7
Level of education		
Incomplete primary education	2	13.3
Complete primary education	6	40
Incomplete high school	2	13.3
Complete high school	3	20
Technical course	2	13.3

Children with disabilities were between 5 and 24 years old, therefore also from different age groups. Eight were male and thirteen were wheelchair users, a more frequent condition among people with profound intellectual disabilities. All had intellectual disabilities characterized as severe or profound, according to the criteria of the American Psychiatric Association [APA] (2014).

Data collection

The sociodemographic profiles of participants and their children were investigated using a structured questionnaire on age, self-reported skin color, marital status, level of education and religion.

Qualitative data collection was conducted using semi-structured individual interviews (Turato, 2011). The initial question of the interviews was: "How did you feel when you realized that your child had a disability?" and, based on this question and the interaction established with the interviewer, the participants' free reflection and expression was encouraged. As some topics that interested us specifically might not be spontaneously mentioned, when this happened these topics were actively presented to the participants: a) perceptions about access and care received in health services; b) relationships between family members c) receipt of possible financial support; d) perceptions about help from

relatives (outside the family nucleus), friends or neighbors to take care of family members or the household; e) use of support services for people with intellectual disabilities and satisfaction with these services; f) spiritual, religious, cultural values of the family with regard to the child's disability; g) eventual interruption of career or professional training to take care of the child and, if so, how it was; h) family leisure and entertainment activities and the involvement of the child with intellectual disability in these activities; i) family involvement with community groups, clubs or associations and satisfaction with social interactions; j) perception of some type of discrimination or prejudice.

The topics were proposed adapting the lexicon to the different socio-educational characteristics of the interviewees. The open way of proposing the topics, with no time limit for answers and comments, sought to promote the deepening of the expression of the personal meanings held by them. The interviews, which lasted from 30 to 73 minutes, were recorded and transcribed verbatim. The structured questionnaire, the audio recordings of the semi-structured interviews and the respective transcripts constituted the research corpus that was analyzed.

Data analysis

To address the *corpus*, a thematic content analysis technique was applied (Turato, 2011), seeking manifest meanings and inferring content from the interviewees' speeches. Part of this analysis was inductive, seeking to directly codify the individual meanings expressed by the participants, grouping them into themes, by similarity. Part of the analysis, however, was deductive, when we sought to associate the themes formulated with the three theoretical pre-categories, addressed in the article's introduction and used because they are widely present in the literature on coping: a) problem-centered coping; b) emotion-centered coping; and c) coping centered on interpersonal relationships.

Interviews were analyzed and coded one by one by two researchers, initially independently. The individual analyses were discussed, gradually developing the set of themes. This dynamic led, in the view of these researchers, to the presumption of theoretical saturation of the results, considering that there were enough elements to achieve the proposed objectives and, at the same time, the finding that no more significant data emerged for the formulation of new themes (Turato, 2011). Based on the frequency of appearance in the interviews, the five themes most present in each pre-category were selected (Chart 2) to be discussed with support from the literature and the clinical experience of the authors.

Chart 2. Most frequent themes in the interviews according to the three pre-categories of types of coping.

	Themes	N*	M**
Problem-centered	Seeks professional support for the child	14	41
	Care prioritized to the detriment of professional and personal life	15	33
	Change/adaptation of family dynamics	13	34

		N	M
	Seeking expert guidance and clarification	13	29
	Maintenance of maternal routine as a positive coping strategy	8	13
Emotion-centered	Insecurity/difficulty sharing care for the child	13	28
	The child with a disability is the center of the mother's life	12	27
	Feeling that they do their best help in coping	9	19
	Preservation of privacy by sharing less information	8	13
	Emotional and volitional adaptation according to the child's needs	5	14
Centered on interpersonal relationships	Seeking support from the extended family	13	45
	Spontaneous affirmative actions - destigmatization	13	32
	Seeking support in their partners	12	29
	Conviviality with other mothers with children with disabilities	9	16
	Giving in to stigmatization	8	16

* N = number of participants who mentioned the theme.
** M = number of mentions to the theme, throughout the interviews.

Results

Pre-category 1: Problem-centered coping

The theme 'seeks professional support for the child' refers to the anxieties and concerns of participants regarding what they considered to be a lack of social, health, transportation and specialized education services for people with severe disabilities:

> We don't have much support from the government. APAE even has good will, but it is not able to give support to a child with very severe disabilities. They have no structure (Intv. 1).
> She does not speak. When she was little, I tried speech therapy through the SUS. I couldn't because, as they know it's something like this for life, they don't make much effort to get a vacancy (Intv. 4).

Another aspect highlighted in the participants' statements was thematized as 'change/adaptation of family dynamics'. It was common among the participants to express the priority given to children in the organization of life and family routine, with great efforts to adapt to the situation having been reported, with changes in habits and life projects:

> We had to adapt our entire lives to her. I sleep until half past four. Then I get up and start doing things with her to give me time to go to work. We think about her, not about us (Intv. 1).

> I adapted the house. You can plan better, but we did everything adapted (Intv. 10).

These changes sometimes meant the interruption of a professional career, an issue thematized as 'prioritized care to the detriment of professional personal life', which seems to closely dialogue with a possible self-blaming of the participants:

> Not everything in life is about working. While I work [...] and my daughter [how would it be]? I think about her a lot (Intv. 5).
>
> I got tired of leaving my daughter alone, as if I were no longer her mother. I felt useless. Then I left the service (Intv. 15).

In contrast to these types of statements, for some participants, working outside the home was perceived as a positive coping strategy, an aspect that was thematized as 'maintaining the maternal routine as a positive coping strategy':

> I continued to work, even with all these things, because I think that if I gave in, I wouldn't have the strength (Intv. 1).
>
> I'm working and it's been very good for my head, for my self-esteem. I'm seeing this with different eyes. Because I lived for her all day long. Not that I abandoned my daughter, but it's been good for me. You see different people, you talk, you exchange ideas (Intv. 9).
>
> Once I started working, I felt a lot better because the day-to-day routine was all around him (Intv. 11).

There were reflections by the interviewees on how much they valued detailed information about the clinical condition of their children, which would improve the care that they themselves could provide. Having quality information seemed to connote, for them, greater ease in the adjustment process to the new life situation. In addition, they reflected on how much the lack of information would have made this confrontation difficult. These aspects were thematized as 'search for specialized guidance and clarification':

> I started attending physical therapy and they taught me a lot. They guided me to position my son. It was a blessing! I learned a lot there (Intv. 7).
>
> He was about three years old when I realized that he couldn't crawl, he couldn't sit, he couldn't walk, he couldn't do anything. I was a first-time sailor and nobody explained anything to me (Intv. 6).

Pre-category 2: Emotion-centered coping

The most frequent theme in this category was 'insecurity/difficulty in sharing care for the child':

> I could pay someone to take care of him, but I don't trust it. No one will know how to take care of him like we do (Intv. 3).
>
> There is that feeling that someone is going to mistreat her for what she has. So, I get scared (Intv. 5).

The themes 'child with a disability is the center of the mother's life' and 'emotional and volitional adaptation according to the child's needs' refer to how much the mothers alluded to putting the child's needs above their own needs and desires. The child's condition would have impacted their lives, changing the way they perceive their existence, attributing to the children's disability the convergence of many of their thoughts, feelings, behaviors and attitudes:

> He is definitely the center of my life (Intv. 2).

I live for her. We [mothers] stop living our lives to take care of them [children with disabilities] (Intv. 8).

Some interviewees declared that they had spared no efforts to promote the maximum development of their child, which generated the theme named 'feeling that they do their best help in coping' seeming to be associated with the feeling of fulfilling a duty:

We always want the best for her. If there was something better, another benefit, I would like it (Intv. 4). I wanted to offer her a better life, I wanted to give her everything. Even if she doesn't walk, I wanted her to grow up knowing that I fought to try to make her problem go away (Intv. 5).

We try to do everything we can (Intv. 9).

Another relevant theme was 'preservation of privacy, sharing less information'. They said they experienced a long exposure of their private lives, told several times to strangers and to health workers and others. They spoke about the need to continuously communicate their search for explanations, feelings of loss of the idealized child, prejudice, indifference, uncertainties, fears and anxieties, not always considered as understood by the interlocutors. These negative feelings led them to select to whom and what to expose about their issues:

If you talk about the problem of a special child, nobody understands, they think you're exaggerating. I prefer not to say anything (Intv. 1).
There were people who asked if she had a problem. If I saw that they asked with love, I explained; if I saw that it was ignorance, I would say 'where are you seeing a problem? I don't see a problem', and didn't give satisfaction (Intv. 15).

Pre-category 3: Coping centered on interpersonal relationships

The perception of the importance of the extended family appeared in the interviews as a normal, expected and natural consequence of the condition experienced by the group:

My sister-in-law helps me a lot. She supports me a lot (Intv. 3).
Apart from me, my husband and children, I have a sister who has always helped (Intv. 14).

In addition to this perception of what we thematized as 'seeking support in the extended family', partners were mentioned as also playing an important role in coping by the interviewed mothers ('seeking support in the partner'):

I always had my husband's support. He was always on my side (Intv. 8).
He [husband] is very important to me. I don't say much so as not to inflate his ego, but he is very important to me (Intv. 10).

Furthermore, it would have been relevant for the participants 'conviviality with other mothers with children with disabilities'. Mothers would have structured an informal support network that allowed them to meet other women who experienced similar situations, sharing experiences and, in their views, favoring adjustment:

The only thing I do is go out to a friend's house who has a special child. For us to vent to each other, tell the things that happen (Intv. 1).
When there is another child like that, the friendship becomes pleasant. When I meet these mothers, I think I get stronger (Intv. 5).

> You talk, you expose things, one opens up to the other. I think it's very good. They go through the same thing as us (Intv. 10).

Another topic raised was named 'spontaneous affirmative action – destigmatization':

> Not that we have to be exposed. But I go to the restaurant, to the party, to the pizzeria. We walk with him (Intv. 2).
>
> Prejudice is everywhere, but if you hide it, it's worse. Then I go. I think a lot before I go, but I go (Intv. 5).

It is interesting to note that this last theme is opposed to 'giving in to stigmatization', in this same pre-category: the idea of not exposing oneself publicly as a way of protecting from prejudice. This contrast highlights a possible conflict experienced by some mothers: going out with a child with a disability can be understood simultaneously as a positive coping mechanism and as an additional stressful event.

> When we go out there is a lot of prejudice. Instead of having fun, we get upset. We prefer not to go out much (Intv. 1).
>
> It is difficult to face society, people look at a lot. I say it looks like an alien. There are people with a lot of tattoos and people don't even care. But you see the disabled person in the wheelchair and it's astonishing (Intv. 10).

Discussion

The first analytical movement carried out on the corpus was associated with an inductive posture on the part of the researchers, reasoning directly on empirical data. A second movement, of a deductive nature, sought a dialogue between the thematized aspects and theorization already present in the literature, concerning the three types of strategies for coping with the stress associated with caring for a child with severe or profound disabilities.

In agreement with previous studies (Santos & Pereira-Martins, 2016), in the present investigation there was a predominance of use of coping strategies centered on the problem and on interpersonal relationships, which were mixed with emotion-centered strategies. Problem-centered coping strategies seem to be usually associated with more active postures and more favorable adjustments (Jaiswal, Subramanyam, Shah, & Kamath, 2018). Faced with the intellectual disability of their children, the interviewees reported seeking professional and family support that would facilitate adaptation, as well as relevant information and action alternatives that would expand their autonomy as caregivers and provide a feeling of control of the situation.

Like other studies (Jones & Passey, 2005; Tilahun et al., 2016), our research suggests a strong perception of the interviewees regarding the lack and inadequacy of health services, lack of financial support and effective professional support to promote the child development. These are major problems to be overcome, in the view of the interviewees. Difficulties in accessing health services and the perception that the quality of care is inadequate can result in an intense feeling of helplessness and be a source of greater stress for caregivers (Nowak, Broberg, & Starke, 2013; Rodrigues, Fontanella, de Avó, Germano, & Melo, 2019). It seems possible that the degree of professional support received affects acceptance, cohesion and the ability to solve problems, influencing adjustment (Jansen, Van der Putten, & Vlaskamp, 2013).

Receiving adequate guidance and information about the disability also seems to help in the adjustment process, promoting positive feelings of security and belonging (Araújo, Paz-Lourido, & Gelabert, 2016; Sivberg, 2002), decreasing the occurrence of dysfunctional thoughts regarding the child's diagnosis and life (Ribeiro et al., 2016), avoiding unrealistic expectations, alleviating anxiety and stress (Tilahun et al., 2016).

The Brazilian Unified Health System (SUS) has been working for some time with policies that induce comprehensive care for people with disabilities. In 2002, the National Health Policy for People with Disabilities was instituted, aimed at the inclusion of people with disabilities in the entire SUS service network (Brasil, 2008). In 2012, faced with the need to expand, qualify, and diversify strategies for the care of people with different types of disabilities, the Care Network for People with Disabilities was established within the scope of the SUS (Portaria nº 793, 2012). These public policies have been systematically dismantled in recent government administrations, including with financing difficulties, which has jeopardized the comprehensive care of people with disabilities and their families (Dubow, Garcia & Krug, 2018). Our interviewees did not seem to consider themselves targets of these policies. On the contrary, their statements seem to be in line with reflections present in the Brazilian literature of a persistent disarticulation of the different components of this network (Machado et al., 2018).

Our results suggest that, in order to face the difficulties aggravated by the lack of professional support, there would have been profound changes in family routines and, in particular, in the lives of the mothers interviewed, who are commonly the main caregivers. Such findings are in line with some reflections already present in the literature, with maternal burden being one of the most constant findings in research that investigates the dynamics of families with children with disabilities (Rodrigues et al., 2019). Mothers, in fact – as we found in our sample – may start to prioritize only the internal issues of family life, to the detriment of their professional lives, being able to leave their jobs (Gondim & Carvalho, 2012) and starting to have their daily lives guided by mothering activities, sometimes designing their existence almost exclusively in terms of care (Guerra et al., 2015). Daily life can be dominated by consequences of the disability, which would interfere with the subjectivity of these women, potentially affecting their self-esteem and sense of self-efficacy, impacting the way they relate to their partner, other children and the rest of society (Santos & Pereira-Martins, 2016).

Our research corroborated the idea of the importance of extended family support (Araújo et al., 2016). This type of informal support, based not on professionals, but on family members and other close people, brought benefits to the mental and physical well-being of the investigated mothers, according to them. Furthermore, also confirming previous findings (Li-Tsang, Yau, & Yuen, 2001), our results suggest that a good bond between the couple would positively impact coping. Cooperation and distribution of household chores, with the participation of all family members in caring for the person with a disability, seem to be important factors for reducing parental stress and maintaining family integrity and balance (Jones & Passey, 2005). We identified, however, insecurities and difficulties of some interviewees in dividing care actions, which, in part, was attributed to the perception of great complexity involved in this care. This is in line with another study with mothers of children with disabilities who were uncomfortable with support from people they believed to be less competent than themselves (Cohen, Holloway, Domínguez-Pareto, & Kuppermann, 2014). In our study, the centralization of care by some interviewees seemed to be a way for them to feel in control of the situation to ensure the best possible care, in their views.

People with severe or profound disabilities require permanent care as a condition for survival and, in this sense, such care can be considered a matter of social justice (Diniz, 2007). Care performed in the private sphere, with an emphasis on solidarity and parental responsibility, refers to a system of 'familism', that is, a bias of primary attribution to the family of the functions and obligations of care (Alves & Mioto, 2015). This has proved to be insufficient to guarantee adequate care for vulnerable groups, such as people with severe disabilities (Diniz, 2007).

In contrast, the condition of dependency and the demand for care can be seen as inherent to the human condition, and societies must structure themselves to accommodate inevitable dependencies with dignity (Kittay, 2015). This highlights the urgency of an ethical posture that guides the relationships between care providers (family members and professionals) and people who demand care, recognizing the notion of interdependence as a value expressing the human condition, both of people with disabilities and those without disabilities. Care would then be an essential good, demanding the development of an 'ethics of care' and reaffirming the importance of a social structure that meets the care needs of dependents and caregivers themselves (Kittay, 2015).

Mothers who have children with disabilities demand emotional support and social interaction (Jones & Passey, 2005). A well-established social and community support network would benefit their physical and mental health (Barbieri et al., 2016; Gusrianti, Winarni, & Faradz, 2018), improving their personal functioning and protecting them from negative effects of stress (Jansen et al., 2013; Santos & Pereira-Martins, 2016). Thus, a coping strategy that can be encouraged is the strengthening of the social support network (Araújo et al., 2016; Barbieri et al., 2016). To improve living conditions and facilitate the necessary adjustment, it is desirable that the interests of these women are valued, promoting well-being, independence and community integration. In this sense, the results of our study suggest that providing greater possibilities and facilities for these women to maintain their careers, if they so wish, can help with the adjustment.

Restrictions on social activities due to dedication to care tasks tend to cause stress and damage to the psychological well-being of mothers (Cramm & Nieboer, 2011), impairing interaction with the community, leisure, recreation and locomotion - isolation that, possibly increases the chance of suffering prejudice. Opposing these problems was also pointed out as necessary by the interviewees.

Still regarding the damage to social relationships, the importance given by participants for conviviality with other mothers who also have children with disabilities is highlighted, seeming to agree that group activities make it possible to share stories, feelings, expectations, experiences and information about care, clarifying doubts, reducing anxieties, contributing to the child's development and strengthening the healthy bond between mother and child (Barbosa, Balieiro, & Pettengill, 2012).

Final considerations

In order to promote more adequate adjustments to the conditions they face, participants pointed to the need for professional support, especially in relation to the health sector, but also in relation to other specific support services for people with disabilities. This gives the demand for care a public and social character, going beyond the exclusively individual and family scope, and should also be the subject of reflections by clinicians.

We observed the participants' demands for objective and appropriate guidance on disability, which would actually promote health education, encourage inclusion and tolerance, and minimize prejudice. The contributions of the participants also point, in our view, to the idea of promoting the formation and empowerment of groups of mothers/fathers, promoting the sharing of experiences, community support, access to rights and the exercise of citizenship.

A limitation of our study is the fact that we investigated a convenience sample consisting only of mothers; future studies including fathers will make it possible to investigate probable gender differences in the coping strategies used. Furthermore, our results stand out due to the specific data collection technique employed; future qualitative research using focus groups and participant observation techniques may raise important additional questions about the investigated coping strategies. Finally, the results of research with clinical-qualitative methodology are restricted by the possibilities of cognitive and affective interaction between participants and specific researchers, including considering the interpretative limits of the latter and the peculiar complexity of variables involved in clinical activities. Empirical studies on families that have children with severe or profound intellectual disabilities are still scarce, particularly in Brazil, justifying the continued expansion of knowledge in the area based on different investigation methods.

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