




## Temporal organization of life in mothers of children with autism spectrum disorder

Organización temporal de la vida en madres de niños con trastorno del espectro autista

Organização temporal da vida em mães de crianças com transtorno do espectro do autismo

Carlos Manuel Osorio García<sup>1\*</sup> , Zaily Leticia Velázquez Martínez<sup>1</sup> , Naila González Portelles<sup>1</sup> 

<sup>1</sup>Universidad Internacional Iberoamericana. México.

<sup>1</sup>Hospital Pediátrico "Octavio de la Concepción y de la Pedraja". Holguín, Cuba.

\* Corresponding author: [cmosoriogarcia.psico@gmail.com](mailto:cmosoriogarcia.psico@gmail.com)

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### ABSTRACT

**Introduction:** mothers of children diagnosed with autism spectrum disorder tend to play the role of caregivers of their children, which could limit their time to satisfy their needs for self-care, recreation and/or as workers by prioritizing the satisfaction of needs of said children. Limitations in the development of temporal organization skills and inequality in the distribution of family functions can lead the mothers of these children to suffer exhaustion, irritability, stress, and anxiety; reasons why attention should be paid to the development of this skill. **Objective:** to characterize the development of the temporal organization of life skill in mothers of children diagnosed with autism spectrum disorder. **Method:** the investigation was carried out between January and June 2020. Mothers of children who study at the "Haydeé Santamaría Cuadrado" Special School in the municipality of Holguín, Cuba participated. It is a qualitative descriptive study of multiple cases. In the process of obtaining

information, techniques such as: observation, pie, composition and semi-structured interview were used. **Results:** mothers organize their time based on their children with autism spectrum disorder, with a tendency towards immediacy. It was identified that the spheres in which they spend their time are family and work, leaving spaces of time for self-care and recreation lacking. **Conclusions:** the people investigated have limitations in the development of the ability to temporally organize life.

**Keywords:** time management; mothers; caregivers; autism spectrum disorder



## RESUMEN

**Introducción:** las madres de niños diagnosticados con trastorno del espectro autista ejercen, como tendencia, el rol de cuidadoras de sus hijos, lo que podría limitar su tiempo para satisfacer sus necesidades de autocuidado, recreación y/o como trabajadoras por priorizar la satisfacción de las necesidades de dichos hijos. Las limitaciones en el desarrollo de la habilidad organización temporal y la inequidad en la distribución de las funciones familiares pueden conducir a que las madres de estos niños sufran agotamiento, irritabilidad, estrés, ansiedad; motivos por los que se debe prestar atención al desarrollo de dicha habilidad. **Objetivo:** caracterizar el desarrollo de la habilidad organización temporal de la vida en madres de niños diagnosticados con trastorno del espectro autista. **Método:** la indagación se realizó entre enero y junio de 2020. En ella participaron madres de niños que estudian en la Escuela Especial “Haydeé Santamaría Cuadrado” del municipio de Holguín, Cuba. Es un estudio cualitativo descriptivo de casos múltiples. En el proceso de obtención de la información se utilizaron técnicas como: la observación, el pastel, la composición y la entrevista semiestructurada. **Resultados:** las madres organizan su tiempo en función de los hijos con trastorno del espectro autista, con tendencia a la inmediatez. Se identificó que las esferas en las que emplean su tiempo son la familiar y la laboral, quedando desprovistos espacios de tiempo para su autocuidado y esparcimiento. **Conclusiones:** las personas investigadas poseen limitaciones en el desarrollo de la habilidad organización temporal de la vida.

**Palabras clave:** del tiempo; madres; cuidadores; trastorno del espectro autista

## RESUMO

**Introdução:** mães de crianças com diagnóstico de transtorno do espectro do autismo tendem a desempenhar o papel de cuidadoras de seus filhos, o que poderia limitar seu tempo para satisfazer suas necessidades de autocuidado, recreação e/ou como trabalhadoras, ao priorizar a satisfação das necessidades dessas crianças. As limitações no desenvolvimento das habilidades de organização temporal e a desigualdade na distribuição das funções familiares podem levar as mães dessas crianças a sofrerem exaustão, irritabilidade, estresse e ansiedade; razões pelas quais se deve prestar atenção ao desenvolvimento desta habilidade. **Objetivo:** caracterizar o desenvolvimento da habilidade de organização temporal da vida em mães de crianças com diagnóstico de transtorno do espectro do autismo. **Método:** a investigação foi realizada entre janeiro e junho de 2020. Participaram mães de crianças que estudam na Escola Especial “Haydeé Santamaría Cuadrado” do município de Holguín, Cuba. Trata-se de um estudo qualitativo descritivo de casos múltiplos. No processo de obtenção das informações foram utilizadas técnicas como: observação, torta, redação e entrevista semiestructurada. **Resultados:** as mães organizam seu tempo a partir dos filhos com transtorno do espectro autista, com tendência ao imediatismo. Identificou-se que as esferas em que passam o tempo são a família e o trabalho, faltando espaços de tempo para autocuidado e recreação. **Conclusões:** as pessoas investigadas apresentam limitações no desenvolvimento da capacidade de organizar temporalmente a vida.

**Palavras-chave:** gestão do tempo; mães; cuidadores; transtorno do espectro do autismo

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## INTRODUCTION

The birth of a child is an event full of emotions and feelings. The expectations that are generated from the knowledge of the pregnancy move the parents and the family to imagine them in general, to represent them. In a way they create their ideal child, even this ideal could be formed long before this stage, but it is at that moment that it is built and rebuilt with greater intensity due to the imminent arrival of the child.

Seeing the descendants grow up healthy, achieving autonomy and independence are some of the concerns of families. Such concerns may cause parents to be more uncertain about their child's future, particularly when the child is diagnosed with Autism Spectrum Disorder (ASD). Having a child with ASD could generate great impact on the family, due to the expectations created, because these are based on the representation of healthy children.<sup>(1)</sup> Faced with this situation, families should organize their time around the needs and characteristics of the child with ASD.

A conscious, critical, rational, rational, generalized, creative and responsible organization of time in each member of the family should allow each of them to perform different functions and roles as parents, professionals and at the same time maintain activities of self-care, leisure and recreation, among others. When the aforementioned conditions are not met and a patriarchal, male chauvinist functioning predominates in families, then mothers are mainly overloaded with activities that could produce different symptoms of stress, anxiety, etc.

Research with mothers who have children diagnosed with ASD is a priority, as more and more children are evaluated and qualified with this disorder and family members need guidance and support to better manage this situation. On the other hand, no systematic research on the development of temporal organization skills in mothers of children with ASD has been identified so far, except for the work of Osorio and Velázquez.<sup>(1)</sup> The scarce scientific production on this topic in this study group constitutes a research gap and a gap in the current state of knowledge.

The present research on temporal organization in a group of mothers who have children diagnosed with ASD assumes the theoretical and methodological references of the cultural-historical approach. For this work, temporal organization is assumed as a skill that configures "personality dynamics (attitudes, values, actions, feelings, etc.) that allow subjects to project themselves intentionally in time and especially to the present future, in various time frames and with the purpose of achieving greater self-management of life".<sup>(2)</sup>

From the cultural-historical approach, the internal structure of the ability proposed by Graf, Iliasov and Llaudis as cited in Fariñas is assumed.<sup>(2)</sup> These authors propose four actions that are presented below.

Sense planning "plays the role of orientation through the motivational hierarchy of the person, of the senses that orient his or her life (sense of life). These hierarchies can be established for different timeframes (long, medium and short)."<sup>(2)</sup>



On the other hand, the function of condition control is described as “the consideration of the situations in which daily activities are carried out, both from a subjective and objective point of view, which allows for a more adequate and realistic organization of life”.<sup>(2)</sup>

The probable forecast is (...) “the delimitation of the time in which the different activities, relationships and tasks of life (dates, schedules) are expected to take place. In other words, it is a sort of flexible anticipation, where it may be convenient to bring forward, postpone, cancel, substitute, include the things one expects to do, as events arise”.<sup>(2)</sup>

Finally, the control of the balance is defined as: “that balance that we make of what we have done, with some degree of frequency and level of awareness”.<sup>(2)</sup>

Consequently, with the assumed referents it is important to highlight the indicators of good temporal organization,<sup>(3)</sup> which form the guiding thread in the analysis of time organization in mothers of children with ASD; these are:

- The possibility of alternating activities for different purposes (productive, intimate-personal communication, rest, recreation)
- The possibility of breaking life routines
- The possibility of planning life routines intentionally
- Awareness of the mechanism of organization and its mastery
- Awareness of aspirations, goals and their achievement within certain deadlines
- The decrease of slopes
- Adaptation to real possibilities (idealism versus objectivity)
- The adequate conjugation of the important with the urgent
- The increase of the capacity to work, to be interested in the things that are done and to enjoy them
- The decrease of stress
- Feelings of accomplishment and the happiness that accompanies them, among others

Assuming temporal organization as a general ability that shapes human development includes in a relevant way the development of personality. It leads to consider the person in the search for mastery of one's own behavior.

The above described serves as a starting point for the formulation of the general objective of this article, which is aimed at characterizing the development of the skill of temporal organization of life in mothers of children diagnosed with ASD.



## METHOD

The methodological strategy followed responded to qualitative epistemology. This perspective attributes value to the singular for the production of knowledge, to the complexity and density of the information systems produced and their relevance for the comprehension of the phenomenon.<sup>(4)</sup>

In view of the above, it was assumed the multiple cases studied as a research strategy, because it facilitated a complete, deep and systematic examination of the way in which the three mothers investigated were configuring their organization of time.

The empirical methods were scientific observation and interview, which made it possible to obtain information on the way in which the subjects organize their time. The techniques used were:

*Observation guide:* it was structured as items to observe the different manifestations of the actions and indicators of good temporal organization of life.

*Semi-structured interview guide:* it was structured with items that responded to the actions and indicators of the skill. For this technique, the mothers were given the questions to answer in the shortest possible time and then the possibility of going deeper into some questions was assessed.

*Cake:* it consists of asking the subject to subdivide a circle into parts, just as if it were a cake, except that the sizes of the pieces do not have to be equal, but they will respond to the amount of time he/she spends on the fundamental activities he/she carries out in his/her life.<sup>(5)</sup>

*Composition:* it was entitled "How do I organize my time?" in order to know and deepen in how the subject organizes his time. The application time varied between 45 minutes and one hour with short interruptions.

In order to develop the research strategy, the subjects were invited to participate in the study, explaining to them the importance of their anonymity and the exclusively scientific use of the information obtained. An attempt was made to gather diverse cases that included, as a priority, mothers who play different roles (home, work, care of the autistic child).

At first, the pastel technique was applied for the collection of information. Secondly, the composition entitled: "How do I organize my time? Finally, the semi-structured interview was applied with the aim of triangulating the information.

The procedure for data analysis was the one proposed by Rodriguez, et al.<sup>(6)</sup> These authors state that, for the analysis of qualitative data, after data collection, the following tasks are performed: data reduction, data arrangement and transformation, and finally obtaining and verifying conclusions.

It should be noted that the initials used to identify the persons investigated in the results section do not correspond to their real names, in accordance with the principles of privacy, confidentiality and protection of personal data.



## RESULTS

This section presents the persons who took part in the research and then develops an integration of the information that made it possible to identify the points of convergence between the three cases based on the analysis of the four actions that make up the ability to organize life temporally.

### *Subject 1: BBH*

Female, white, 40 years old, biparental family with two children one of them with autism spectrum disorder. She lives in the municipality of Holguín, Cuba. Presents average-high economic conditions. Educational level; university, but currently works as a self-employed worker in a business that operates from her home.

### *Subject 2: YEF*

Female, white 31 years old, she lives with her son, mother and sister in the municipality of Holguín, Cuba. She presents average economic conditions, Resident in the specialty of Coloproctology at the General Teaching Hospital "Vladimir Ilich Lenin" of Holguin.

### *Subject 3: AGB*

Subject is female, white, 49 years old. Married (her husband lives Aproad). She lives with her son and her 89-year-old mother. She lives in the municipality of Holguín, Cuba. She has average-high economic conditions. She is a middle-level technician in accounting. Since the birth of the child, she has no labor relationship.

## Integration of the results

The mothers in the study were characterized by having an empirical knowledge of the skill temporal organization of life, i.e., they did not receive training on the skill. In all the cases studied, it was evident how the role of caregiver of the child with ASD conditions and structures the arrangement of time and activities in the various areas where they work. In general, the areas in which they work are work and family, the latter being the area where they spend most of their time and where they are most demanding. There is no time for self-care or insertion in another area that could make their life dynamics more flexible.

The use of the ability was manifested in a limited way and a planning with a tendency to immediacy. Although they are aware of the need to establish a life routine that helps the adaptation of habits in children with ASD, many times, due to the same lack of knowledge of the disease, it becomes a stereotyped routine lacking sufficient stimulus.

The three cases presented symptoms of physical and psychological exhaustion and stress, aspects that were reflected in the composition, in the semi-structured interview, as well as in the observation carried out during the process of applying the techniques.



In the case of BBH and YEF, they organize their time in terms of work, household chores and the role of caregiver, the latter being the common thread that runs through the remaining activities. This was not so in the case of AGB, who structures her time in terms of childcare as a priority and household chores. In this regard, it is important to mention that, although this mother does not have a work relationship, she also plays the role of caregiver for her mother, who is an older adult, which increases her demands and stress symptoms. This state is conditioned by the limitations in the organization of her time and the lack of a family support network.

In all three cases, a limited possibility of alternating activities for different purposes was evidenced, an aspect that is reflected as dissatisfaction, in addition to contributing to the development of stress symptoms. At this point, they place in later stages of development of children with autistic condition (associated to reaching greater independence) the possibility of making their life routines more flexible. This allows assessing the presence of a deficient awareness of the organization mechanism and its mastery, which in turn limits the development of the skill.

All cases reflected inflexible life routines, which can be a stress-generating element, as they become habits lacking reflective analysis; however, AGB evidenced the possibility of breaking life routines. AGB plans activities that provoke enjoyment, both for her son and for herself, which was an indicator of skill development. They set future goals or objectives that mobilize their behaviors and needs.

In all cases, the following were reflected as priority objectives: care, education and development of children with autistic condition. BBH structured other objectives, but in function of their family, living and working conditions. A significant aspect of this case is the absence of their own space to satisfy their self-care and leisure needs, an element that behaved in the same way in all three cases, by establishing routines devoid of an action and judgment based on their interests. BBH reflected the use of means such as work plan and agenda as support for time organization, attributing to the former the learning path in relation to the skill. In the case of YEF and AGB, the use of means of support that facilitate the fulfillment of activities was not identified, which from the researchers' point of view makes it impossible for them to develop a better organization and use of time.

In the case of YEF, short-term objectives were established, although she reported having personal and professional improvement objectives (finishing her specialty and becoming independent), that she does not place their fulfillment in a period. On the other hand, in the case of AGB, her only objective was structured in terms of her son's development. One element that (was found to be affected) was flexible planning in the three mothers; this was expressed on the one hand in pending activities and, on the other, in difficulties in restructuring their routines. Limitations in this sense could affect the improvement of exhaustion and stress states.

The control of conditions was characterized because in the cases of BBH and AGB they prioritized material conditions and, in the case of YEF, they prioritized subjective conditions. The consideration of both conditions (material and subjective) could contribute to the effectiveness of time organization.



On the other hand, in relation to the control of the execution of their activities, only BBH executes it on a daily basis, while the other two cases do not make any control. For this, BBH does not use any means. The systematic use of instruments in the control of balance could contribute to the breaking of routines in a flexible way; the effective prioritization of activities; the reduction of stress; the emergence of feelings of accomplishment and the happiness that accompanies them, and the use of time.

## DISCUSSION

The arrival of a child with ASD can affect family functioning and that of mothers in particular. These infants require different care, with well-established codes and routines. The expectation of the family is the birth of a healthy child to whom dreams and aspirations are attributed, but with the diagnosis of ASD, hopelessness and uncertainty may emerge. These feelings will remain to a greater or lesser extent over time depending on the personal characteristics of the parents and the support received. The presence of a child with ASD in the family environment constitutes a limiting situation, because it implies a permanent tension that tests the resources for family development.

The results presented in this article made it possible to show a perspective of personal/family education and its manifestation in the development of the skill temporal organization of life in an environment of people with ASD, based on the daily experiences of a group of mothers. This information could sensitize the scientific and educational community to a necessary topic that constitutes a space of concern due to the number of cases that are constantly diagnosed.

Much has been written about the role of the caregiver and, specifically, of mothers of children with ASD from several dimensions: quality of life,<sup>(7)</sup> quality of life and work overload,<sup>(8,9)</sup> emotional well-being,<sup>(10)</sup> anxiety and coping styles,<sup>(11)</sup> stress management,<sup>(12,13)</sup> consequences in the caregiver of people with ASD,<sup>(14)</sup> depression<sup>(15)</sup> and others. Specifically, little has been found on the skill of temporal organization of life, only the work of Osorio and Velázquez.<sup>(1)</sup> This topic acquires special interest if this skill is conceived as a personality infrastructure and as such, a factor that often determines the achievement of life projects with efficiency and effectiveness.

The information gathered here can contribute to the design of intervention strategies, both educational and clinical, for the treatment and orientation of mothers and families in general, who live with a person diagnosed with ASD. Campaigns could be designed for the population with the aim of contributing in different ways as support for these mothers.





A limitation of this research is the sample with which we worked: only three mothers. A larger sample could contribute to make generalizations and establishing conclusions about the factors that mediate the adequate development of the skill of temporal organization of life and its influence on the reduction of symptoms of burnout and stress. However, the results shown serve as a reference for future research and allowed an analysis of the diverse characteristics surrounding these three families; which makes it possible to understand the particularities of each individual, their opportunities, and sources of personal and economic support, life projects and the meaning of life that orients their actions.

These results are coherent and converge with those presented by Osorio and Velázquez,<sup>(1)</sup> in that symptoms of physical exhaustion and stress were also identified. In addition, it was determined that the mother investigated had limitations in the development of her ability to organize her life temporally, mainly because medium and long term probable planning, as well as control of conditions, were the two actions that were most affected.

In relation to the research by Miele and De Arruda, et al.<sup>(8,9)</sup> on quality of life and work overload it was shared that the value of family support or support from other agents is relevant to reduce the symptoms of exhaustion and discomfort that cause the quality of life to be evaluated as fair, because they feel overwhelmed or that they do not have enough time to carry out their daily tasks. However, it was considered that there are multiple factors that influence this evaluation and that the quality of life could be qualified as bad or good depending on the support networks that each mother has and other factors that intervene in this variable.

It was evidenced in this article that stress symptoms are present in mothers of autistic children, as identified by Schieve, et al. and Zaidman-Zait, et al.<sup>(12,13)</sup> and that the perception of both economic and social support can contribute to its reduction; an aspect which was also corroborated by Bujaico<sup>(7)</sup> in his research on quality of life. The above idea reaffirmed the need to implement governmental strategies and programs that are interested in this topic and create policies that favor caregiving mothers of infants with ASD. In addition, the need for the completely family group to be organized in terms of sharing obligations and household chores became evident.

Based on these reflections, it is suggested that future researchers continue to investigate the relationship between the development of the temporal organization of life skill and variables such as quality of life, stress, anxiety, depression, life projects, and sense of life, hopelessness or social support. It is also interesting to carry out quantitative correlational studies with large samples of diverse contexts. These aspects could provide analyses with figures that would make it possible to demonstrate the prevalence of the problem and the points of contact and divergence between the case studies.



## CONCLUSIONS

This article presented the results of a study aimed at characterizing the temporal organization of life skill in mothers of children with autism spectrum disorder, showing that: the mothers who participated in the study dedicate 60% of their time to the care of their children and that they plan their time with a tendency to immediacy. It was determined that the indicators of analysis of the skill temporal organization of life that prevail in the three cases analyzed are the feeling of accomplishment and the happiness that accompanies it, the possibility of planning life routines intentionally and the awareness of aspirations, goals and their achievement mainly in the short term.

On the other hand, it was identified that the spheres in which the women investigated spend their time are family and work, leaving no time for relationships with friends, leisure and self-care activities that would make it possible to reduce the symptoms of stress and physical and mental exhaustion they have.

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**Conflicts of interest:**

The authors declare that there are no conflicts of interest.

**Authors' contribution:**

Carlos Manuel Osorio García: conceptualization, data curation, formal analysis, research, methodology, supervision, validation, visualization, writing - original draft, writing - revision and editing.

Zaily Leticia Velázquez Martínez: conceptualization, data curation, formal analysis, research, methodology, supervision, validation, visualization, writing - original draft and editing.

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