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Autistic Spectrum Disorder in the Context of Pandemic by Covid-19: Caring for Children and Caregivers

José Vilelas

Abstract

The COVID-19 pandemic has brought important challenges to society and families, with repercussions on child behavior and development with special importance for children with neurodevelopmental disorders that affect and impair the child's functionality: Autism spectrum disorder. Thus, we set as objective to Identify and analyze the scientific evidence of interventions performed on children with Autism Spectrum Disorder in the context of a Covid-19 pandemic. A search was conducted in the MEDLINE, PubMed, CINHALL databases and gray literature. Children with Autism Spectrum Disorders (EAP) may become more anxious, agitated and unregulated with the change in routines to which they are subjected in this phase of the Covid 19 pandemic. Autism disorders affect communication, social interaction and behavior, usually with a tendency to be repetitive and routine, but in a scenario of pandemic and social isolation, anxiety and agitation may be more pronounced and, in more severe cases, there may be less capacity to function. It is important that the family of the child with ASD propose cooperative activities or resources that they have at home and that can be adapted. The insertion of some tasks contributes to the establishment of the ability to play independently. In it, the child gets involved independently. And so it prevents negative behaviors from occurring due to leisure and the need for attention, also favoring concentration.

Keywords: Autism spectrum disorder, children, COVID-19, parents, support

1. Introduction

Autistic spectrum disorder (ASD) is a psychiatric problem that used to be identified in childhood, between 1 and a half years and 3 years, although the initial signs sometimes appear in the first months of life. The disorder affects the level of communication, interaction with others and learning capacity, the child's adaptation to new situations and the display of stereotyped and restricted behavior. This description is reinforced by Leo Kanner, in 1943 who defines autism for the first time as a disorder in children that was manifested by the inability in the relationship and in the acceptance and adaptation to changes. They are children with physical development equal to that of other children but have great limitations in social or affective relationships, causing social isolation. In 2013, the Diagnostic

and Statistical Manual of Mental Disorders (DSM-5), aggregates as four separate previous categories: autism disorder, Asperger's syndrome, childhood disintegration disorder and generalized undefined development disorder, in a single concept of Autism [1]. Although it appeared to be a rare disease, the prevalence of ASD has steadily increased. In this context and in the face of the pandemic, children and families needed to reorganize themselves. The World Health Organization said the new coronavirus (COVID-19) was a global pandemic on March 11th, 2020 [2]. In Portugal, children were forced to stay at home with the closure of schools on 13th March. Some of them received daily tasks from their teachers, while others attended classes by videoconference. In addition, the portuguese government started broadcasting classes on television [3]. Despite the attempt to maintain access to universal education, some children who needed special education were hampered by the absence. In addition, with the adaptation of the health system, children with neurodevelopmental diseases, such as ASD, their therapies were suspended.

The child with ASD does not have a physical disability, looking perfectly normal. Therefore, understanding autism becomes more complex. Even to try to understand a child with autism it is necessary to consider their individual needs. However, these children have some genetic diseases associated with autism. This situation is due to the existence of a multifactorial genetic factor and several organic causes related to its origin. Thus, reinforcing the previous idea of children with autism spectrum disorders, the prevalence of associated diseases is about 2.5 times higher than in the general population [4]. The repercussions of the pandemic may be of more concern to children suffering from mental illness and development. Sudden changes in daily routine have consequences and can potentiate existing symptoms, increasing the risk of emotional, behavioral and relationship complications. With such special and peculiar characteristics, these children need help, specialized and continuous support in their most affected areas. In this way and due to the times in which we live due to the public health situation by Covid-19 and for reasons of quick action to prevent and minimize a major outbreak of infection and contagion, these children are more susceptible to the development of serious forms of COVID- 19 [3].

COVID-19 is caused by a coronavirus that can induce SARS in humans: SARS-CoV-2 [5] first reported in Central China in December 2019 [6]. Due to person-to-person transmission, it quickly spread across Europe [4], with northern Italy becoming the epicenter of Europe [7] and the USA [8]. As of May 1st, 2020, more than 3 million cases have been reported worldwide, affecting more than 200 countries. Currently, in October 2020, the USA has approximately 9,500,000 cases, followed by China with around 8,500,000 cases, Brazil with 6,000,000 cases, Russia with 1,700,000 cases, and Portugal in Portugal with 142,000 [9].

Since the beginning of the pandemic, most clinical and research efforts have been devoted to understanding the properties of the virus and its pathogenicity to treat the infection and prevent its spread [10].

However, according to some research evidence, the COVID-19 pandemic has revealed a worsening of the mental health of citizens in general [11]. The repercussions of the pandemic can be even more worrying in children suffering from mental illnesses and development. Sudden changes in daily routine have consequences and can potentiate existing symptoms, increasing the risk of emotional, behavioral and relationship complications [12]. The COVID-19 pandemic has brought important challenges to society and families, with repercussions on child behavior and development, the dimension of which we do not yet fully understand. The effects on children's mental health derive from several factors: concerns about the disease itself and uncertainties about contagion [13] and lethality, as well as measures taken to minimize its impacts, such as isolation and social distance [14]. In addition to the threat to the physical health of the general population, the pandemic has boosted a

plurality of psychological responses by the progressive increase in confirmed and suspected cases such as compulsory confinement at home or in health facilities, the decrease in the availability of personal protective equipment and/or the exhaustive coverage of the media capable of causing our alert and fear system to be constantly activated [14]. It is important to note that the pandemic required unprecedented measures by governments, including imposing quarantine on citizens [15].

The search for innovative approaches and the need to ensure continuity of care for children and young people with chronic health problems, should not be underestimated during the pandemic. A specific response is needed to minimize the mental suffering of children and young people who are quarantined.

Specialist Nurses in Child and Pediatric Health Nursing in partnership with Specialist Nurses in Mental Health and Psychiatric Nursing must design and develop socio-culturally appropriate programs to define strategies that facilitate the way to intervene in mental suffering and provide psychosocial support nursing care, to mitigate the adverse effects of prolonged isolation in children and young people [16].

The COVID-19 pandemic led families to adapt their lives, including social isolation and work from their parents' homes. The consequences of this confinement on mental health are still unknown [17].

Among vulnerable populations, children and young people with autism spectrum disorders are a group of special concern for the impact that the outbreak of COVID-19 may have on their well-being, as well as the specific support they may need to preserve their mental health during the pandemic [18].

Children and young people with autism spectrum disorders have problems with social communication, difficulties in maintaining social interactions and unusual patterns of repetitive behavior. These characteristics are associated with a preference for highly predictable environments, while children and young people may feel stressed, anxious or confused if unpredictable or complex changes occur [19]. The outbreak of COVID-19 has undoubtedly led to a fast-paced and rapidly changing social situation, which can increase the difficulties of children with autism spectrum disorders.

In view of the above, we intend to respond to the following objective: Identify and analyze the scientific evidence of interventions performed on children with Autism Spectrum Disorder in the context of a Covid-19 pandemic.

2. Methods

A search was conducted in the MEDLINE, PubMed, CINHALL databases, using a search strategy to identify studies published between January 2019 and December 2020, in Portuguese, English and Spanish. Studies that described interventions in children with autism spectrum disorders in the context of a pandemic by Covid-19 were included. 21 articles were selected using the PRISMA method. Gray literature and other articles researched in the Google Scholar, were also included.

3. The impact of environmental changes and disrupted routines during the COVID-19 pandemic

Children and young people with autism spectrum disorder are vulnerable to the effects of prolonged isolation or quarantine, and may have difficulties adapting to this new routine, especially since inflexibility and a great reluctance to change are hallmarks of this disorder [20]. All of these practices leading to decreased

transmission of the coronavirus (SARS-CoV-2) negatively affect children and young people with autism spectrum disorder, but also their families, including siblings. Prolonged isolation increases the risk of losing daily practical skills; in the case of children with Autism Spectrum Disorder, it can also lead to an increased risk of disruptive behaviors such as depression and anxiety, and difficulty in relationships with peers, manifested by isolation, anger and aggression [20]. It is known that physical contact and socialization are fundamental to the well-being of all human beings, but children with ASD are particularly vulnerable because harmful changes in the environment can negatively affect their social, cognitive and emotional development. Children with special educational needs may need additional support to adapt to new routines and to understand changes. The most susceptible youth may develop symptoms of anxiety, depression and, in some cases, obsessive-compulsive behaviors.

Some authors recommend that you can combat the adverse effects of isolation through [7, 20, 21]:

- Do everything possible to keep children/young people active, reprogramming their daily routines in a way that incorporates activities that can be performed at home, including occupational, motor and recreational activities (for example, self-care and personal hygiene, house cleaning, care for a pet and exercise). Using a “visual agenda” can be a great help, with the inclusion of sequences of images, drawings, or written messages that illustrate, in advance, what will happen during the day. To plan the entire week, other visual aids can be used, such as personalized calendars.
- Maintain, as far as possible, the same daily routines (for example, getting up at the same time, having breakfast, doing intellectual and physical activities, relaxing, eating, doing new tasks, leisure and dining).
- Maintain contact, by phone or computer, with teachers, with health professionals, as well as with other people who are important to them.
- Use social networks, such as Facebook or Instagram, moderately, to keep in touch with other people.
- Carry out occupational, recreational and sport activities at home, in order to maintain a similar routine that previously existed.
- Consider that the fact that the child/young person with autism spectrum disorder is in constant contact with other people during the isolation period may lead to the need for some time alone, time for themselves. In these circumstances, a space and time appropriate to their privacy needs should be promoted.
- To increase the likelihood of children/young people feeling motivated to be active, they must be involved in the planning process for their days.

In a study of 527 parents of children with autism spectrum disorder, with the aim of investigating the impact of the COVID-19 outbreak on these children, carried out in northern Italy, one of the most affected European regions, concluded that the majority of children who had 13 years old showed a decrease in autonomy and in the ability to carry out structured activities. After COVID-19, parents reported that their children had more intense (35.5%) and more frequent (41.5%) behavior problems, with about 20% having to go to health institutions [22].

During the COVID-19 pandemic, strong attention should be paid to the potential and resources existing in the communities and not to their weaknesses and vulnerabilities. In this regard, efforts should be made to create or maintain safe and protected environments for children/young people with autism spectrum disorders. One of the measures is the use of masks; DGS recommends its use from the age of 10 [23]. These children may have difficulty accepting and/or using masks appropriately and continuously, which are a fundamental health and hygiene rule for outings and activities carried out outside the home. To get used to its use, it may be useful to adopt a gradual approach to the use of these articles, progressively increasing the time of use and resorting to positive and motivating reinforcements for their use. As for the masks, if a person does not accept to use anything strange on the face, it is suggested to introduce the use of it in regular activities, applying it gently over the nose and mouth without squeezing. When the child/young person accepts its use, their behavior should be reinforced, for example, praising. As time goes by and the child/young person feels more familiar with the use of the mask, it can adjust to the proper position of total protection of the nose and mouth. It is recommended that the intention to use the mask be repeated several times a day, explaining in advance the need for its use (for example, communicating that it is a new way of preparing to leave) or creating a situation in which you remember when it is necessary to wear the mask outside the home. The forms of communication should be adjusted as closely as possible to the person's support needs (pictograms, objectives, verbal information, ...). It is also essential that professionals and teachers use their own mask to show the child/youth how it should be used, acting as a reference and motivating element [24]. As for hand washing and respiratory etiquette, the child/young person with autism spectrum disorder should be advised on specific actions and behaviors for controlling the pandemic. Visual support can be used to complement the parents' explanations. It is important to develop a routine with the child/young person and make hand washing a priority. Parents need to be aware that this activity will take some time to make it an habit, but children/young people learn when taught by example. This measure should be considered a family activity and the parents' participation in this routine is very important. The norm of hand washing can be difficult for children/young people with autism spectrum disorder, because the process generates some confusion, either due to the increase in the time it takes, as the steps involved in the technique, result in increased stress in children/young people and the desire to avoid the process [25].

4. Caregivers of children with autism spectrum disorder in the context of COVID-19

As for the family of the child/young person with autism spectrum disorder in the context of COVID-19, parental stress is greater in parents of children/young people with autism spectrum disorder when compared to parents with children who show typical development [26].

In a study by Colizzi, Sironi and Antonini in 2020 it was concluded that parents' stress was still related to the risk of job loss, economic uncertainty, lack of adequate health resources, and increased time to access intervention programs could impair the ability of the caregiver or parents to deal with the child/young person in the context of Pandemic [22].

Parents face several challenges generated by COVID-19. One is the transitions in lifestyle changes caused by social isolation and the adoption of new routines that the child/young person with autism spectrum disorder was not used to. These transitions and changes in routine can be very disturbing, aggravating the behavior

of children/young people, such as the increased frequency of crying and aggressive behaviors such as reactive strategies and even the refusal to transition [27]. While some parents reported that their children adapted without major problems, thinking of this period of the pandemic as a break from school or vacation, other parents reported that their children were uncomfortable with the transition. Other parents also reported that their children immediately felt the effects of the interruption in their routine as an impossibility to go to school, to see teachers and friends. The mood and behavior of children/young people changed immediately, showing anger, confusion, sadness and exhibiting more hyperactivity [26].

While we can predict that parents' stress will be greater during the pandemic, we also recognize that there are ways for parents to combat and deal positively with daily stressors. Pottie and Ingram in 2008, identified coping responses that can elevate the parents' mood: social support, positive restraint, focus on the problem, emotional regulation and making a commitment. Simultaneously, the authors identified four coping responses that reduced positive mood: escape, guilt, inhibition and lack of support [28].

In Italy, parents, due to the suspension of educational and rehabilitation services during confinement caused by the pandemic and the consequent isolation, expressed having experienced some challenging situations, namely problems with Internet connection (19%), ignorance about the use of the web (17%) and difficulties in following the instructions given by health professionals (22%). The emotional burden faced by parents during the pandemic involved mainly the fear of being alone and caring for children with special health needs without the support of an expert [29].

In the study by Parenteau, Bent and Hossain in 2020, parents reported positive and negative techniques for dealing with COVID-19. To face the transitions that the pandemic caused in their family routines in a healthy way, parents resorted to: exercise (walking, cycling, yoga), meditation, prayer, reading the newspaper, participating in virtual groups to connect with the community, friends and therapists. For families who had more than one caregiver at home, some parents suggested the idea of alternating between rest intervals so as not to get too overwhelmed [26].

Finding positive ways to cope with illness and isolation can be beneficial for parents and children/young people with autism spectrum disorder.

With the challenges that arise for children/young people with autism spectrum disorder and that they have online support/classes, many families have decided to concentrate their efforts to work on the skills of daily living. With more time at home, families can start or deepen the development of self-care activities in children/young people, be present to reinforce and clarify doubts and provide reminders [27].

In an observational, cross-sectional and analytical study carried out in Portugal by Amorim, Catarino and Miragaia in 2020 to a total of 99 parents of school-age children, two groups were formed: one of parents of children with ASD and the other of parents of children without neurodevelopmental problems. The average age of the children participating in the study was 10.75 ± 3.13 years and 68.7% male. Most fathers had university degrees (62.9% of mothers and 61.1% of fathers). Emotional dysregulation was also a common problem experienced by children with ASD and was associated with problems of inadequate adaptation. In addition, anxiety and depression were the most prevalent affective disorders in these children. It is also known that school demands and social commitment are stressors for children with ASD. So you can imagine that staying at home during quarantine, away from these challenges, can comfort these children. However, in that period, these children had to live with a great stressor for them: the change of routines [30].

For parents with children/young people with ASD, quarantine means not only serving as their child's teacher, but also serving as a special educator, social skills trainer, speech therapist or behavioral/mental therapist, sometimes with little support from professionals [31]. Children with ASD generally require more intensive services and support than children with typical development, which can intensify parents' tension during the pandemic.

The pandemic is changing several factors closely associated with person-environment suitability. These factors include balancing the needs of children/young people with autism for routine and environmental predictability versus the unpredictability associated with the pandemic; learning or working styles of autistic individuals versus opportunities available at this time; and the living environment or activity schedules among family members.

As we have seen, changes in daily routines and restrictions on the regular environment interrupt a number of domains as physical health, mental health and family factors. For example, sleep dysregulation, reduced access to specific foods will impact selective feeding by children/young people with ASD, which may lead to reduced food intake, poor nutrition or worsening problems of elimination and constipation. Restricted access to regular programming, activities and preferred locations contributes to the decrease in physical activity, which is already a concern among children/youth/family, as well as higher rates of obesity [32].

Maintaining typical routines as it has already been demonstrated is impossible during the COVID-19 pandemic. However, the impact of changes in routines can be mitigated by the joint creation and implementation of alternative routines, incorporating regular bedtime and morning hours, attention to sensory stimulation, adequate but limited exposure to the media, regulated times of watching TV and game viewing and attention to regular hygiene, food and water intake, daily exercise and sleep. Maintaining social networks (even if the only viable option to do this is online) is essential for children/young people/autistic and their families [33].

COVID-19 has become a pandemic and many governments have declared restrictive measures to prevent its spread. For parents and children, staying at home is one of those measures. In this situation, the treatment of young children with special needs, such as autism can be a challenge for families and caregivers.

Autism is increasingly among us and close to all of us; at home, in schools, in families, in society and in the world in general. What is extraordinary about the times in which we live due to the public health situation by Covid-19 and because of quick action to prevent and minimize a major outbreak of infection and contagion, leads us to rethink the school, the reality, our actions, our priorities, the different ways of acting in order to minimize a worsening at the psycho-emotional level and behavioral responses in children and young people and other population that are part of a group, which is no longer as a minority, as was initially believed by the statistical data, for the researches presented of the significant increase of children with Autism Spectrum Disorder, in the current world.

Families with children with autism spectrum disorder face a number of challenges with the rise of the COVID-19 pandemic, including the explanation of the pandemic and the need to ensure and monitor safety measures for children in an understandable way, building a structure at home to minimize social isolation. These children usually have to undergo specific interventions by health professionals. However, at this moment, due to contention measures, both families and children with autism are limited in face-to-face professional support.

These routine changes can cause them profound suffering. For this reason, all of us (parents, nurses, other health professionals and researchers) must be united and quickly establish new methods and functional routines to enable children with autism spectrum disorder to be safe and at peace.

5. Maintain the safety of children with autism spectrum disorder in a pandemic situation

Currently, we all live in a time of uncertainty related to the covid-19 pandemic situation. These are particularly challenging times for all of us and for children with autism spectrum disorders, this is no exception. Children with characteristics of the autism spectrum have greater difficulty in dealing with uncertainty and changes, as previously mentioned. In this phase in which your routines have changed profoundly and in which therapies, support and consultations have been suspended or are taking place in a different way than usual, it will be important to pay special attention and respond to your needs.

Thus, the pandemic caused by the new coronavirus poses numerous challenges in guaranteeing the fundamental rights of children. In order to prevent the overload of health systems and to protect those who are most vulnerable, States must establish policies to combat Covid-19 in an agile way to minimize the contagion as much as possible, a fact that is unfeasible based on the general population, but also based on the peculiarities and rights of children with autism spectrum disorder.

Some of these measures can be adapted to reconcile the fight against coronavirus with the rights of children. The best way to fight the disease has been through preventive actions, following some control and protection measures such as hand washing and hygiene, wearing masks and social isolation as a way to prevent the spread of the disease. These measures are currently widespread [34].

The COVID-19 pandemic has generated a series of changes in the lives of families and society in general, which may impact not only on physical and biological health, but also on mental health. As an example, social isolation and other recommendations, necessary for the prevention and reduction of disease transmission, end up significantly modifying daily life, which may result in tension, fear, stress and anxiety, both for caregivers and children with TEA [35].

For this specific population, it may be difficult to understand the pandemic scenario and all the ramifications resulting from COVID-19, especially when it comes to young children and/or those who have intellectual and sensory disabilities concomitant to the condition [36].

It is important to note that autism is not a risk factor for COVID-19. Thus, children with ASD have symptoms similar to those of other young people without the disorder. However, the characteristics of autism can create difficulties in adopting preventive measures. An example is changes in sensory functions. An autistic child may have a great interest in the smell, taste and texture of objects, and it is common to observe him passing his hand over everything and bringing the utensils to his mouth. This practice increases the possibility of contamination and parents must be aware of hygiene issues, keeping the environments ventilated and avoiding sharing objects [34].

Thus, children and adolescents with ASD can be considered more vulnerable to COVID19, not because they are susceptible to the complications of the virus, but due to the characteristics of the clinical picture that weaken the understanding of the pandemic scenario as well as the control and protection measures, exposing them to greater risks of contamination. In this sense, considering the particularities present in this picture, all the existing complexity and the current pandemic scenario, it is essential to reflect on the impacts of this global health crisis on the daily lives of this population, since they naturally already experience very difficult and challenging situations.

The control and protection measures adopted by countries to contain the spread of the virus and contagion of the population need to be carefully managed to avoid

the intensification of psychological distress in families and behavioral difficulties in children with ASD. In this direction, the text presents ten tips that aim to help families deal with these children during the pandemic, such as explaining children about what the disease is, organizing daily activities, having time for play activities, using games for teaching, online therapy, among others [18]. Another author says that the process of social isolation and its implications in the lives of children with ASD, depend on personal, contextual, political aspects and mainly on the current health systems. Children with autism may show strong resistance to change. The closure of kindergartens, schools and other facilities that children with autism attend daily can create additional tension. In addition, the author points out that the current moment has mobilized the community to develop solidarity actions and to deal with the invisibilities of the most vulnerable populations [36].

Safety measures must be enforced by parents. These are the example for the child with ASD. This technique is called live modeling. If the child is interested in videos, this is a resource that can also be used. Hand washing as we have seen is extremely important and therefore parents should wash their hands as recommended by specialists and record each step of this activity. The process list is a guide to start learning the child with ASD. Recording the video of the child performing the process can be a way to improve their learning. The child's help should be gradual and little by little it should promote the child's autonomy. It is very important to provide these children with compensation for the goals achieved, this motivates the child to do more and better [37].

It is reinforced that adopting these measures is fundamental not only for the protection of these individuals, but also of the family and community. However, due to the difficulty of understanding and, in some cases, the presence of important sensory issues, some children and adolescents with autism will not be able to use the mask and/or remain in social isolation for a long time.

In Portugal, people with intellectual, developmental or autism spectrum, with a degree of disability equal to or greater than 60%, as evidenced by a multi-use certificate, are exempt from the use of a mask or visor in places that generally require it [37].

In addition to these sensory challenges, masks also create new social communication challenges. Autism spectrum disorder can include impaired visual perception skills, making the chances of accurately reading another person's facial expression under a mask, from a socially appropriate distance, more difficult than normal. In addition, when seeing another person's face while they are wearing a face mask, the eyes are the main area of the face that is visible. Individuals with ASD often have difficulty making eye contact, adding yet another obstacle for them in the realm of social communication. These factors can cause communication problems and frustration. As masks drown out voices, verbal communication also becomes more difficult. Fortunately, there are several strategies that can make using a face mask more bearable.

As we have seen, the impact of the pandemic can be even more worrisome in children suffering from autism spectrum disorders. Sudden changes in daily routine have consequences and can potentiate existing symptoms, increasing the risk of emotional, behavioral and relationship complications.

Children with special health needs may need additional support to adapt to new routines and to understand changes.

In the future, with the opening of schools and the return to routine, it is essential to create a balance between the public health measures necessary to minimize the impact of the pandemic and the gradual resumption of interpersonal relationships and school, professional and leisure activities, maintaining the child safety.

6. Conclusions

The child with ASD in Covid-19 is experiencing an extremely difficult situation with their families. Everything that we as health professionals believe is important and emerging to be worked towards in order to better adapt their functionality, we now have enormous restrictions in enhancing their capabilities, in removing them from rigid patterns of behavior, stereotypes, rituals and isolation. It is not easy, however it is important not to forget, that even though it is not ideal, it is possible to work with them, through strengthening the parental potential, enabling parents for the tasks, promoting cooperation between family, school and professionals, by digital platforms, and by the technologies and social networks to which we have access, or even by telephone and by mail, to get closer, to guide parents and together, we reduced some of the inherent difficulties, making it possible to be close, thus continuing to develop activities and tasks that, if they were in a school context, they would possibly be carrying out, so as not to lose the essential routines, such as, for example, parents establishing waking times, cleaning times, structured task times, promoting playful and relationship moments and broader, if the nuclear family allows it, without calling into question public health guidelines. The pandemic risks widening inequalities for children, particularly in vulnerable groups. As such, this presents an opportunity to redress the imbalance and support children and families' wellbeing as we emerge into the 'new normal' world.

As we have seen, the impact of the pandemic can be even more worrisome in children suffering from autism spectrum disorders. Sudden changes in daily routine have consequences and can potentiate existing symptoms, increasing the risk of emotional, behavioral and relationship complications.

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