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Role of the social worker in dealing with children with Autism Spectrum Disorder

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Abstract

The main purpose of this study was to examine the social work professional intervention for autistic children. Here, what is the role of the social work professional in working with children with developmental disorders such as autism? was investigated. Furthermore, the distinctive features (clinical features) shown by such children, and the effect caused by this disorder, were investigated. For this study, 20 children with autism, their 05 parents and 05 social workers working with such children in institutional premises were used as the research sample. Colombo district of the Western Province was used as the field of study, and children with autism referred for speech therapy were used, where professionals working with children with mental disorders were used as institutional social workers through purposive sampling method. Key informant interviews and non participant observations were used for data collection. For this qualitative study, narrative analysis

method was used for data analysis. Theory of Mind Deficit and the social motivation theory were used for theoretical analysis. According to the findings of the study, clinical features of autism can be identified through social communication, social interpretation and creative playing and flexibility of thoughts. Parents of these children are the most affected by autism. They can recognize the effect of this in 03 ways, which is the impact on parents' psychological well-being, their social life and on the relationship between the parents. Also, even siblings and other family members face problems while living in the family corporation. Social worker dealing with clients with autism, his/ her role can be played under counselling, **information providing, coordination, advocacy**, case managers, school assistants and group work. The study made it clear that the social worker needs special knowledge and training for working with such clients.

Key words: *Autism Spectrum Disorder, Social work, Mental disorders and Mental health professionals*

1. Introduction

Humans go through various developmental stages during their lifetime. Among those stages, “childhood has become such a distinct period that is hard to imagine that it was not always thought of as markedly different from adulthood” (Santrock, 2011, p.06). The development of a child during childhood affects his or her entire life. But the lack of proper development of children’s life leads to the impairment of children’s well-being.

When examining the society, it can be recognized that some children are facing developmental deficiencies or developmental disorders. Among them, autism spectrum disorder (ASD), attention deficit hyperactivity disorder, mental retardation and special learning difficulties are commonly recognized. Due to the developmental disorders, children as well as their close relatives are under a lot of pressure. Also, the same effect starts from the child and spreads throughout the entire society. Therefore, through this research paper, an analytical commentary on autism spectrum disorder has been discussed as it appears in society is presented. Meanwhile, the role of the social worker who can play a special role in supporting such children is discussed.

Autism spectrum disorders (ASD) are a diverse group of conditions. They are characterized by some degree of difficulty with social interaction and communication. Other characteristics are atypical patterns of activities and behaviours, such as difficulty with transition from one activity to another, a focus on details and unusual reactions to sensations (WHO, 2022).

Also, it is “a childhood neurodevelopment disorder. This is considered to be the reason for this, due to a problem of neural development in the child’s brain, which develops outside of the normal way” (Damsinghe, 2008, p.13). A child’s brain is not fully developed at birth, and it develops in the first few years after birth. It is determined by genes. Environmental factors also influence the brain activity to be carried out to the maximum. If the environmental factors are not properly obtained, it is difficult to achieve the maximum expression of the genes. In the case of autism, despite these environmental factors, the brain does not develop properly. This shows a higher tendency to affect boys compared to girls. Also, at present, this situation can be recognized in many countries. This stunts the overall development of a child. Therefore, these children fail to demonstrate abilities and development compared to other children of their age.

2. Methods and materials

The main purpose of this study was to examine the role of the social worker in working with children with autism spectrum disorder. Furthermore, the distinctive features shown by such children, and the effect caused by this disorder, were investigated. For this study, 20 children with autism, their 05 parents and 05 social workers working with such children in institutional premises were used as the research sample. Considering the clinical characteristics of children with autism, it is difficult to use severe level children for this study. Therefore, mild level autism children are used in this study. Furthermore, some parents of such children refused to respond to the study, and interested parents and social work professionals were used for this purpose.

For this study, the Colombo district of the Western Province was used as the field of study, and children with autism referred for speech therapy were used, where professionals working with children with mental disorders were used as institutional social workers through purposive sampling method. Key informant interviews and non participant observations were used for data collection. This was conducted as a qualitative study and the narrative analysis method was used for data analysis.

Theory of Mind Deficit and the social motivation theory were used for theoretical analysis. Theory of Mind (ToM) is a multifaceted skill set which encompasses a variety of cognitive and neurobiological aspects. ToM deficits have long been regarded as one of the most disabling features in individuals with Autism Spectrum Disorder. One of the theories that attempts to account for these impairments is that of “broken mirror neurons”. The aim of this review is to present the most recent available studies with respect to the connection between the function of mirror neurons in individuals with ASD and ToM-reflecting sensorimotor, social and attention stimuli)Andreou and Skrimpa, 2020, p. 01(.

The social motivation theory holds that motivation among people originates from the interrelationships of behavioral, biological, and evolutionary forces. Given that social motivation is an intrinsic factor, it determines human behaviours, and consequently, the level of motivation among individuals (<https://ivypanada.com/essays/social-motivation-theory-and-implications/>).

3. Results and Discussion

Childhood can be recognized as a crucial period in human life. Disruption to personal development during this period will have negative effects on the entire life span. Children suffering from developmental disorders based on biological causes or other causes interfere with the overall well-being of the child. ASD, which is basically discussed here, can also be called a developmental disorder that hinders the overall development of the individual. Thus, basically, what is autism spectrum disorder and what are the clinical features shown by such children are examined. Also, the effect of autism on children with such disorders as well as the effect on other parties will be discussed.

Considering the study data, it was clear that the parents of children with autism as well as other parties related to them were not well aware of the clinical features of this disorder or how to identify such children (04 parents in the study sample). The study also revealed that even if they suspect that their child has a disorder such as autism, parents do not want to admit it (05 parents in the study sample). Therefore, it is important to examine the clinical features of autism and make awareness about the public.

A child with autism spectrum disorder can be diagnosed at the age after about one and half years old. Therefore, such children show the characteristics of a normal child in all respects and show normal physical development from birth until about one year. It is clear that this condition also causes the parents to not want to accept the changes caused by autism later on. This developmental disorder directly affects the child's communication skills, social interactions, intellectual skills and motor activities. Also, three common files of autism show symptoms, namely:

- Social communication
- Social Interpretation
- Creative playing and flexibility of thoughts (Damsingha, 2008, p.15).

Children with autism have weak interpersonal skills especially in nonverbal communication. They usually do not look directly into other people's eyes and are not able to respond to external stimuli such as smiling, screaming and expressing surprise. They find it difficult to make contact with outsiders, to build relationships with peers and to be happy when others are happy because they are not able to understand nonverbal cues. These children show differences in their development in communication skills. Characteristics of this include late speech or non-speech, inability to begin speaking, inability to maintain speech and obscure language skills.

According to the DSM V classification (Diagnostic and Statistical Manual of Mental Disorders), the following characteristics should be considered when diagnosing a child with autism.

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers. Specify current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behaviour.

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or preservative interests).
4. Hyper- or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement). Specify

current severity: Severity is based on social communication impairments and restricted, repetitive patterns of behaviour.

- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make co morbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level (American Psychiatric Association, 2013, p.50).

Also, the clinical characteristics of children with autism can be further explained using Theory of Mind Deficit. One of the most common and most researched theories of autism is the Theory of Mind (ToM), hypothesis developed by Simon Baron-Cohen. This was originally developed when researchers were examining characteristics that may or may not be unique to the human species. The idea was that an individual with a theory of mind should be able to identify mental states within themselves and others, and use this information to make predications regarding others' behaviour (Premack & Woodruff, 1978).

A deficit in theory of mind results in individuals on the autism spectrum performing less well on tasks that require 'mind reading' compared to their typically developing peers. A deficit in Theory of Mind means that individuals with autism may struggle in the following areas:

1. Explaining their behaviors
2. Understanding their emotions
3. Predicting the behaviors or emotional state of others
4. Understanding the perspectives of others
5. Inferring the intentions of others
6. Understanding that behavior impacts how others think and/or feel
7. Differentiating fact and fiction (<https://www.simplypsychology.org/theory-of-mind.html>)

Due to these deficits, explicit teaching regarding how to understand the emotions of others and how to problem solve in social situations is a necessity. Strategies such as visuals, role-play, or social narratives to remind individuals with ASD about emotional states or appropriate behaviors can be useful.

In addition, parents and teachers working with individuals on the spectrum should be careful not to place blame on behaviors that have repercussions that are not fully understood by that child or adult. Consider explaining how behaviors impact others or make others feel before reprimanding.

According to the observations of the study, the following clinical features were commonly identified in children with autism.

Table 3.1. Clinical features shown by the sample

S.No.	Clinical features	No. of children in the sample
1.	Speaking a low number of words	20
2.	Lack of physical growth	06
3.	Lack of active communication	20
4.	Waiting for the caring hand	08
5.	Not responding to external stimuli or taking too long to respond	20
6.	Not demonstrating age-expected skills	20

Source : (study data, 2021).

According to the social motivation theory, motivation is originated from the interrelationships of behavioral, biological, and evolutionary forces. Thus, children with autism, are not motivated neurologically to response social stimuli. Therefore, it is obvious to see the above symptoms.

Considering the physical development of these children, it was clear that the majority of the children in the study sample showed physical development relative to their age. It was also clear that a minority of the children in the study sample wanted the help of another person to get something done. It was confirmed that the other children were not so sensitive about it. By considering the above table, it is clear that autism affects the overall functioning of a child.

There can be identified three levels of autism; mild, moderate and severe. This can be further identified through the following table.

Table 3.2. Levels of autism spectrum disorder

Severity level	Social communication	Restricted, repetitive behaviors
Level 3 “Requiring very substantial support”	Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and minimal response to social overtures from others. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approaches.	Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interferes with functioning in all spheres. Great distress/difficulty changing focus or action.
Level 2 “Requiring substantial support”	Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions; and reduced or abnormal responses to social overtures from others. For example, a person who speaks simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.	Inflexibility of behavior, difficulty coping with change or other restricted/repetitive behaviors appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress and/or difficulty changing focus or action.
Level 1 “Requiring support”	Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social	Inflexibility of behavior causes significant interference with functioning in one or more contexts. Difficulty switching between activities. Problems of

	<p>interactions, and clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to-and-fro conversation with others fails, and whose attempts to make friends are odd and typically unsuccessful.</p>	<p>organization and planning hamper independence.</p>
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Source - (Reynolds and Kamphaus, 2013, p.02).

Children belonging to level 1 (13 children) and level 2 (07 children) could be identified in the study sample. Accordingly, although their clinical features appeared to be almost the same, differences in severity could be identified.

4. The impact of autism spectrum disorder

Since children with autism show unusual behaviours that are beyond normal, it has a special impact on the parties involved in daily life activities with the child. Among these, the child’s parents are directly affected. Accordingly, it is clear that due to such situations, this has a negative effect on the child as well as on other parties who come in contact with the child.

4.1. Impact on parents

Since the conception of a child, the only wish of any couple is to see a healthy child born into this world. But some complications can arise from children based on various reasons. In such cases, the parents of these children can be mentioned as the main affected party. As it emerged, the change became a very stressful situation for the parents. The impact of children with autism on parents could be identified in 03 main ways. That is,

1. Impact on parents’ psychological well-being
2. The impact on the social life of the parents
3. Impact on the relationship between the parents

(Field data, 2021).

It is clear that being a mother or father of a child with autism has a negative impact on their mental well-being. They are constantly regretting their child's behavioural uniqueness and comparing their child with normal children.

“When I see other children of our baby's age, I feel great fear and sadness for my child. There are countless times that I wonder how good it would be if my child was like this” (A 29-year-old mother of an autistic child, 2021).

And having a child with behavioural characteristics that deviate from the expected nature of the parents has caused them to be under stress.

“Actually, my husband and I have been waiting for a child for 03 years and we got this child. In the beginning, my baby did not have any defects. But after 02 years, these changes started to be seen in the baby. We were very worried then. We were under a lot of pressure because of that” (A 34-year-old mother of an autistic child, 2021).

According to this, after realizing that her child is autistic, this mother explained the facts to her husband, but at first he did not want to accept it. However, when the condition was eventually discovered to be autism, the condition became very painful for them.

Also, such children show the nature of autism usually after some time of their birth, so parents face a mental struggle in the face of such situations. That is, parents are mentally oscillating between thoughts, thinking whether the child is normal or abnormal. Therefore, the study revealed that parents often do not accept this situation and develop a number of irrational thoughts. Those irrational thoughts can be expressed as follows.

- Their child cannot develop autism
- Thinking that this condition of the child is normal
- Thinking that the child's situation become normal in the future
- Thinking that the child may have developed this condition due to impurity

It is clear that parents have used such facts as prevention strategies. In order to heal the child, the parents engage in various rituals. It is clear that they are trying to fill the educational gap through religious practices based on the problematic situation caused by the child.

It was also possible to identify that the parents were uncomfortable due to certain traits shown by their children. Parents say that they are very uncomfortable due to the complaints of the other children's parents because of the violent behaviour of their autistic children. Also, if such children do not get what they expect, they behave violently and engage in self-harming activities such as hitting those around him, biting his head. Behaviors of children that cause mental distress to parents can be further stated as follows.

- Communication deficits
- Weaknesses in dealing with society
- Lack of interest
- Limited range of behavior
- Monotonous behavior patterns
- Lack of curiosity
- Lack of awareness of surroundings
- Sleep abnormalities
- Fearful personality
- Socialization problems
- Lack of capacity and talent development
- Self-concept issues
- Problems expressing positive emotions such as happiness and enjoyment and reluctance to create them (Field Data, 2021).

The fact that parents have an expected thought about when such behaviours will appear and constantly thinking about whether such behaviors will cause inconvenience to another party has caused parents to be constantly stressed. Furthermore, it was confirmed that one of the mothers in the study sample could not bear this situation and even became anxious.

This situation has also affected the social life of the parents of children with autism. There, it became clear that the statements made by saying that the behavior of certain parents has influenced the child to become autistic have also caused the parents to limit their social interaction.

“All the relatives of our lady started blaming her because she wore tight jeans when she was having a baby and this child happened like this. Later he refused to go to the houses” (A 35-year-old father of an autistic child, 2021).

It is clear from such matters that there is little knowledge about conditions such as autism and that causes the relatives of autistic children to feel uncomfortable in such situations. The study revealed that the child's socialization is restricted due to certain different behaviors of the child as well as the child's outstanding behavior patterns in the society, and because of that, the parents' socialization is also limited. Here you can see the rejection of various attempts and encounters in the society. It was also seen from the parents that they did not want to talk about the child in public and avoided or denied such opportunities.

It can also be seen to avoid children of their own age and their family members. And it was clear that the majority of these parents (04 parents) think that having children with autism is a cause of social stigma. The pitiful responses of the society for the children have also become a matter of shame for the parents. Because of this, one thing that is clear is that the parents' communication network is limited due to the child's disability. Also, all the three mothers belonging to the study sample have quit their jobs for the sake of the child. The main reason is that such children need a special care system. Also, it is clear that it is necessary to provide this kind of care system to the child so that the parents miss even some of the original friendship relationships.

Furthermore, the study confirmed that the abnormality of the child has also affected the emergence of certain problematic situations between the parents. Because taking care of the child is a very tiring process, the person who takes care of the child from among the parents frequently quarrels with the other party, scolding saying that one of the parents is responsible for this condition of the child, and if another child is born, that child will also be disabled like this child. It was also possible to identify the distance between the parents of sexual relations based on the fear of being victimized.

But parents who face these situations positively could also be identified in the study. There the preparations made by them for their child can be stated as follows. That is,

- Counseling, referring the child for speech therapy
- Constantly stimulating the child and institutionalizing the child whenever possible
- Expanding the current knowledge of autism (Field Data, 2021).

It is clear that the way parents interpret their children's problems and the existing ideologies about their responsibility and role will change the reactions of parents towards autistic children as well as the impact on them.

4.2. Effect on other parties

A child with autism affects their parents as well as the various parties who are close and in constant contact with them. Studies show that siblings of children with autism also face problems due to these disorders. There the brothers and sisters are alienated from the society because they are a brother or sister of a child with autism. It became clear that these children were given nicknames based on their brothers.

“I have two children. This child is the second in the family. A lot of friends make fun of the older child because of the younger son. There was a time when my eldest son was told that he could not go to school because his friends called him the crazy boy's brother. We stopped it when we went to school” (A 38-year-old mother of an autistic child, 2021).

Also, it was also possible to identify cases where some children lose social opportunities because of these children.

“The elder son is rarely invited to birthday parties by such friends. If you tell him the reason, you have to tell your little son too. He doesn't say much to the elder son either because he will cause trouble if he goes” (A 38-year-old mother of an autistic child, 2021).

Also, if a family member or a relative lives in the same house with the child, it was clear that they also face various challenges because of these children. Also, if a family member or a relative lives in the same house with the child, it was clear that they also face various challenges because of these children. In one case, it was revealed that a marriage proposal to a little one of an autistic child was rejected due to the abnormality of this child. This is because the proposed party believes that these disorders can be transmitted from generation to generation.

“My sister got a proposal. After they saw the baby, they didn't like it. They were told that those diseases can be passed from generation to generation” (A 35-year-old mother of an autistic child, 2021).

It was clear that some of the child's behaviors are dangerous and the freedom of the family members is limited, that such children have some influence on the family members.

5. The role of social work in autism

Since autism is a condition that cannot be completely cured, it is important to prepare such parties to cope with it successfully. Also, "it is a long-term social responsibility to educate, prepare and help not only the child, but also the child's closest relatives, parents, elders, teachers, friends, and the entire society" (Damsingha, 2008, p.27). When treating children with autism, medications, cognitive behavioral therapy, behavioural management therapy, speech therapy, social skills training, occupational therapy and family therapies can be used.

Especially, the role of the social worker should be discussed here. Social work can be identified as an art, science and a profession which supports people in different levels. This profession aims to enhance the wellbeing of people. When people face life struggles and challenges, social workers support them to cope with those issues. According to the International Federation of Social Workers (IFSW) and the International Association of Schools of Social Work (IASSW), social work is defined as follows: "Social Work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing" (International Federation of Social Workers and International Association of Schools of Social Work, 2014).

The social worker also has the ability to mediate in the field of mental health. Consideration should be given to working with children with developmental disabilities such as autism. Mainly, the social worker should have knowledge about mental disorders such as autism as well as good training on it. That is, the social worker should have some clinical knowledge about the social work profession as well as mental disorders.

"I have learned about mental disorders separately. Also has received training to work with people with autism. Otherwise, it is difficult to deal with such clients" (A 38-year-old social worker who works in an institution, 2021).

It is important to identify such children in the early stages to provide good guidance to such children as well as to make them reach the necessary services. In mediating such complex problems, the nature of the problem must be assessed before taking

the necessary measures. The intensity/level of the client's autistic condition and its impact on the child and other parties should be assessed. In mediation for such complex problems, the social worker can mediate in several ways.

- Counselling
- Information
- Coordination
- Advocacy
- Case managers
- School assistants
- Group work

(<https://thespectrum.org.au/autism-support-services/professionals/social-workers>).

Counseling has become a distinct subject area, but within the social work profession, the social worker has to fulfill the role of counsellor when necessary. The social worker has to perform this role on behalf of clients with autism as well as their families.

“I have a diploma in counselling. Thus, I know counselling and how to practice it. As a social worker, it becomes a professional support for me” (A 33-year-old social worker who works in an institution, 2021).

considerations for the treatment of an individual with autism, it includes awareness of the individual's communication and reading abilities, eliminating noise and visual stimuli that could be distracting and, if the individual takes medication, making sure it has been administered if necessary. And here primarily the social worker should provide individual counseling as well as family counseling services. Family members of children with autism must develop the necessary strengths and mental makeup to cope with the condition.

The client should also be provided with the necessary information to provide professional support as well as to connect them to the necessary services. In carrying out these tasks, the social worker should be equipped with the knowledge of the disorder as well as professionals working in autism.

The social worker is also responsible for coordinating these. There the social worker should prepare the bridge of connection with those services. The client can also play the role of advocate in securing the rights of the client in necessary cases. The social worker can act on behalf of the client as well as their family members in case of any legal requirement as well as rights protection. Also, Linking parents and families

with agencies and programs that can help them in times of need is another task of a social worker.

Children with these developmental disabilities are often exposed to professionals in the school system. There, the school social worker has a unique role. There, the role of identifying such children is primarily important. Also, the school system should be adjusted so that such children can be integrated into the school system. Teachers as well as parents should be informed about how to work with such children. And mediation should be done in building relationships between other children in the school and such children.

As mentioned earlier, while considering and managing cases of children with these disorders individually, the social worker can do group work for children who have faced such problems in general, as well as their family members, especially parents. Thus, it is clear that the social worker can perform his professional role in a large area.

6. Conclusions and further recommendations

This study examined the role of the social worker in working with clients with developmental disorders such as autism spectrum disorders. In that, it was confirmed that the role of the social work professional is interdisciplinary as well as inter-professional. It was also revealed that the social worker should have an understanding of mental health and clinical psychology beyond the knowledge of social work when working with such clients. It is essential for the social worker to have a thorough knowledge of such mental disorders as well as training in the nature of dealing with such clients. Also, in a country like Sri Lanka, a broad awareness of the mediation of a social worker in dealing with such mental health problems should be further established.

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