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Cultural Model of Disability – Origins, Assumptions, Advantages

ABSTRACT

This article aims to describe the cultural model of disability. In contrast to the social model of disability, which is strongly coherent, the cultural model of disability has not yet been specified, despite ongoing discussions on cultural determinants of understanding disability. In the first part of the article, the origins and essence of the cultural model are presented. Next, the four main assumptions underlying the model are characterised: 1) people perceive reality through the prism of their culture and experience acquired with it, 2) disability can have different meanings depending on what kind of discourse constitutes its meaning, 3) disability does not mean a feature of an individual, but a category of human differentiation, which can be embodied and thus materialised, 4) instead of just “looking” at people with disabilities and asking what problems they are struggling with, and what support from the society they need, the current perspective should be broadened and include the entire society and its culture. The final part of the article highlights the most important advantages of the cultural model of disability.

Keywords:

disability, culture, society, model, interdisciplinary approach

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INTRODUCTION

Is it possible to create a model of disability that would integrate all its physical, psychological, political and socio-cultural dimensions? In order to attempt to implement this task, two initial assumptions should be made.

Firstly, there is no difference between able-bodied and disabled people. At least in specific periods of life, every person is exposed to various damage and dysfunctions. Additionally, every person experiences a decline in efficiency over the years and more often develops various diseases. Disability is an inherent feature of human nature, and mortality is an inevitable essence of being. Undoubtedly, acceptance of the omnipresence of bodily limitations opens a new perspective in research on disability.

The second assumption can be expressed as follows: people with disabilities should have a real influence on how disability is understood by society and how they are treated by society. The able-bodied majority should respect the right of the disabled to decide about their matters. It should be remembered that people with disabilities constitute 15% of the entire human population, which means there are currently 1.1 billion of them worldwide.

This article aims to present the cultural model of disability, which started in the middle of the first decade of the present century and proposes a broader view of disability than before. I start by showing the origins and essence of the cultural model of disability. Next, I characterise its four main assumptions. In the final part of the article, I present the most important advantages of the cultural model, both in theoretical and practical dimensions.

ORIGIN AND ESSENCE OF THE CULTURAL MODEL OF DISABILITY

Until the 1960s, the medical model of disability dominated². In this model, disability is identified as impairment of the body and the psyche. It is treated as a “medical condition”, expressing itself as a “deficiency” or “deficit”. Considering disability in terms of a deviation from the psychophysical norm leads to severe consequences in social practices and individual biographies, as people with disabilities are perceived as “incomplete”, “defective”, or “deficient”. That, in turn,

² By this model I mean a representation that reflects, copies or somehow illustrates the pattern of relationship perceived in data or in nature. The value and usefulness of the model understood in this way results from the predictions that can be made on its basis and from its function in directing research and developing theories. (Reber & Reber, 2005, p. 397).

means that they should be subjected to appropriate “remedial” actions – treatment, rehabilitation, correction. In the medical model, the social model of disability was completely ignored. The consequence of such a reductionist approach is the impoverishment of the disability phenomenon and the people affected by it. They are reduced to the role of “objects” of influence by various specialists: doctors, rehabilitators, educators, psychologists, speech therapists and others. Disability becomes “a problem situated in the individual it concerns, his/her ‘personal tragedy’, which requires the intervention of professionals, who are the perpetrators of a positive change” (Wiliński, 2010, p. 36). Undoubtedly, the medical model of disability contributed to the formation of prejudices against the disabled and their discrimination.

A profound change in understanding the essence of disability occurred at the turn of the 1960s and 1970s due to the emergence of emancipation movements for people with disabilities. These movements developed simultaneously and independently both in the US and Great Britain. In the United States, the emancipation movement was started by numerous violent protests over significant delays in implementing the rehabilitation law prohibiting discrimination against people with disabilities in public life, especially in the workplace. The enactment of the law in 1973³ granted citizenship rights to people with disabilities, integrated their scattered organisations and laid the foundations for the American version of the social model of disability as a “minority model”. “According to this model, the disabled are treated as a discriminated social minority that defends its own matters, and at the same time, does not abandon the help of non-disabled people and specialists” (Twardowski, 2018, p. 102).

At the same time, disabled people from Great Britain presented their point of view in debates on disability, and in 1975 they created an organisation called the Union of the Physically Impaired Against Segregation (UPIAS). In 1975 UPIAS published a manifesto titled “Fundamental Principles of Disability”, where the following statement expressing the essence of the position of this organisation was presented: “from our perspective, it is society that handicaps physically disabled people. Disability is built on top of our handicaps by the fact that we are unnecessarily isolated and excluded from full participation in society”. Intensive activities carried out by UPIAS and the physically disabled academics associated with: Michael Oliver, Victor Fenkelstein, Irwing Zola, Geof Mercer and Collin Barnes resulted in developing the British version of the social model of disability. The

3 This act, referred to as the Rehabilitation Act, was replaced by a new one called The Americans with Disabilities Act, (ADA) in 1990.

key element of this model is the distinction between physical impairment and disability, understood as the result of oppressive treatment by the social environment. The classification: impairment-disability, proposed by UPIAS, is binary and is similar to the division into biological sex (sex) and socio-cultural sex (gender), adopted from feminist theories. Impairment is inextricably linked with the body and its condition. It is an existing and natural fact. However, disability is understood as a “reaction to impairment dynamically taking place in the social space” (Zdrodowska, 2016, p. 389).

Undoubtedly, the social model has played an important role in researching people with disabilities⁴. It has been significantly developed within the framework of interdisciplinary Disability Studies, undertaken by representatives of various scientific disciplines: sociology, pedagogy, psychology, anthropology, political science, cultural studies and others. According to Philip Ferguson and Emily Nusbaum, “through scientific research, artistic creation, education and activism, Disability Studies try to increase understanding of disability in all cultures and historical periods, promote a fuller awareness of the experiences of people with disabilities and support social change” (Ferguson & Nusbaum, 2012, p. 71)⁵.

Over the past two decades, there have been many critical comments on the social model of disability. Among others, the model was accused of neglecting impairment as an important aspect of the lives of the disabled and not taking into account the individual perception of disability. These allegations are well illustrated by the statement by a disabled feminist, Liz Crow: “Most of us cannot just pretend that impairment is irrelevant because it affects every aspect of our lives. We need to find a way to incorporate it into our overall experience and identity, concerning our mental and emotional well-being and, our ability to overcome it” (Crow, 1996, p. 207).

In 2001, the World Health Organization (WHO) adopted the International Classification of Functioning, Disability and Health (ICF), which raised hope for a complete and coherent model of disability. The ICF classification is based on a functional model of disability known as bio-psycho-social⁶. In this model, dis-

4 Over the last three decades, other models of disability have been formulated, such as: human rights – based, relational, functional, identity, social policy, bio-psycho-social (Wiliński, 2005; Smart & Smart, 2007; Relief & Latosa, 2018). The mentioned models are, to a greater or lesser extent, varieties of the social approach to disability.

5 Recently, Disability Studies have been enriched with the so-called “Critical Disability Studies” expressing interest in disability among representatives of the arts and humanities, as well as medical sociology and social psychology (Goodley et al., 2017).

6 A detailed analysis of functional models of disability was presented by Mateusz Wiliński (2010, pp. 37-50).

ability is treated as a three-dimensional phenomenon resulting from the mutual, dynamic relationships between a person's health condition, mental features, and the social environment. Unfortunately, the bio-psycho-social model of disability raises reservations. For example, Marzenna Zaorska (2015) wonders how to understand the state of disability if the psyche functions correctly, but the body is inefficient and limits human activity. Moreover, are we dealing with a disability if the psyche works efficiently, but the body does not, and the person has difficulties in social functioning? The author also poses a more fundamental question: "What are the relationships between disability, disease and health?" (Zaorska, 2015, p. 24). The conclusion that the WHO has not developed a comprehensive model of disability seems justified at this point.

Critical views on the International Classification of Functioning, Disability and Health have contributed to the emergence of a cultural model of disability⁷. The model creators are Sharon Snyder and David Mitchell from the University of Chicago. According to the authors, the ICF classification proposes a disability model that maintains the status of a health problem, requiring specialised interventions based on standards relating to non-disabled people and their living environments. The classification does not "take into account countless differences between cultures" and "ultimately it can only depoliticise disability by creating 'objective' measures of the body" (Snyder & Mitchell, 2005, p. 9). In the cultural model, impairment and disability are not treated as clearly separated categories that automatically lead to social discrimination against the affected person. There is no search for a term that would only describe the disadvantageous social situation of people with disabilities (disability). In the cultural model, it is understood that impairment is both the human difference facing environmental barriers and the socially mediated difference that gives people with impairment a group identity, and the research of these people – a phenomenological perspective. Representatives of the cultural model believe that disability should not be treated in terms of medical pathology or social discrimination. Snyder and Mitchell (2005) do not negate the role of impairment abnormalities in the structure or functioning of the organism in the development of disability. However, they advocate seeing impairment as "potential materiality" that can be embodied in the body, resulting in pain, discomfort or inability to perform certain activities, but it may also lead to

7 The term was first used by Patrick Devlieger (2005). The author spoke in favor of a creation of a cultural model of disability as a multiple model, i.e., allowing research on disability on three levels – the individual, society and culture. According to Devlieger, extending the scope of the current research is necessary because disability is "an integral part of culture" (Devlieger, 2005, p. 6).

social discrimination against the affected person. In this aspect, the cultural model of disability differs significantly from the social model. The basic drawback of the social model was the rejection of the relationship between impairment, i.e., the physical state of the organism, and disability being the effect of oppressive treatment by the social environment⁸. Thus, it can be said that the cultural model of disability breaks the impairment-disability division, because it sees both biology and culture “as factors remaining in mutual relations, also in conflict” (Plichta, 2017, p. 24). Undoubtedly, the cultural model enriches the current understanding of disability. It points out that research on disability must consider how disability is understood in a given culture and how people with disabilities function in that culture. Moreover, an important question is how people with disabilities build their identities when confronting the understanding of fitness commonly accepted in a given culture.

MAIN ASSUMPTIONS OF THE CULTURAL MODEL OF DISABILITY

Undoubtedly, the best way to understand a new model is to determine how it differs from the previous ones – the medical and social models. It should be noted that each of the models is reductionist. In the medical model, the phenomenon of disability is reduced to the characteristics of the human body. It is assumed that the disability is internal and objective, and the purpose of aid interventions is to “repair” the individual. In turn, in the social model, the phenomenon of disability is identified with barriers, prejudices and discrimination. It is believed to be external and subjective. Therefore, the most appropriate form of assistance is to adapt the environment to the needs of people subjected to oppressive treatment. In both models, the causes of disability are reduced to one group of factors. This attitude has severe theoretical and practical consequences because “it leads to ignoring certain aspects of the phenomenon of disability which are crucial both for understanding what a disability is and for explaining its causes and consequences” (Wiliński, 2010, p. 33). There is one more very significant drawback of both models of disability: an apparent underestimation of the role of cultural practices within society and for society and the impact of these practices on understanding disability.

⁸ The opinion of supporters of the social model of disability is well illustrated by Michael Oliver’s statement that “disability has nothing to do with the body” and: impairment is nothing but the physical state of the body” (Oliver, 1995, pp. 4-5).

The cultural model being developed in the last 16 years is the answer to the imperfection of models of disability. Admittedly, as early as 1994, the British sociologist Tom Shakespeare postulated the need to research cultural representations of people with disabilities. Still, only the work of Snyder and Mitchel (2005) initiated the creation of a theoretical framework for a cultural model of disability. In contrast to the medical and social models, characterised by high consistency and precision, the cultural model of disability is defined poorly. Supporters of this model do not seek to “define disability in any specific way, but rather focus on how different concepts of disability and fitness function in the context of a specific culture” (Relief & Latos, 2018, p. 6). The theoretical framework of the cultural model of disability has not been clearly specified yet. In the remainder, I present four main assumptions of this model, noticeable in discussions on the cultural determinants of understanding disability.

The first assumption of the cultural model of disability was taken from the theory of social constructivism. According to it, people perceive reality through the prism of their culture and the experience acquired with it (Berger & Luckmann, 2018). When people interact, they exchange their visions of reality and develop points of view. Consequently, what a person believes exists or does not exist is determined by the beliefs they have acquired in their relationship with members of their culture. Thus, the world is always perceived subjectively. People attribute specific meanings to what they perceive. Social reality is created in constant interpretation. For example, a blind person will be perceived and understood differently by a doctor, a young child, an adult seeing, and another blind person. For example, in the United States, until 1964, people with black skin were deprived of full citizenship, and their different status was widely accepted. It is worth adding that people with disabilities and women and people of different sexual orientations remain in this situation in many countries worldwide. Supporters of the cultural model of disability are particularly interested in discovering social artefacts, i.e., manifestations of the functioning of a given culture. Artefacts of symbolic significance are of particular interest to cultural anthropologists and sociologists dealing with a disability. For example, a typical behavioural artefact of giving a person with crutches a priority to walk through the door can be understood as a gesture of help or respect, but it can also be interpreted as a sign of pity or a stigmatising gesture. It means emphasising the efficiency of the person giving priority and the weakness of the person to whom the priority is given. Generally speaking, without any in-depth analysis of the manifestations of the functioning of culture, it is impossible to determine how the phenomenon of disability is understood in

a given culture and why people with disabilities are treated in this culture in this and no other way.

The second assumption of the cultural model of disability comes from the concept of discourse by Ernest Laclau and Chantal Mouffe (2007) and can be expressed as follows: discourse constitutes the identity of individual entities⁹. The authors used the statement of Ferdinand de Saussure’s theory of linguistic structuralism that there are no positive concepts in language, only differences. For example, in order to explain who a man is, one should indicate his opposite, i.e., a woman. The authors believe that all social problems should be considered from the perspective of a discourse, which they broadly define as “a socially constructed system of semantic field, a system that defines the framework for shaping the identity of various objects and practices” (Żółkowska, 2014, p. 11). Thus, disability can have different meanings depending on what kind of discourse constitutes its meaning. In the medical discourse, it will be impairment or dysfunction of the body. In the social discourse – a consequence of physical barriers and oppressive treatment. In the emancipatory discourse – the right to self-determination. In the political discourse – the right to enjoy full civil rights. If there were not so many discourses on disability, no one would think about its essence.

Some supporters of the cultural model of disability use the category of “empty signifiers” present in the discourse theory. They believe that such terms as “efficiency”, “disability”, “impairment”, “limitations of activity”, “limitation in fulfilling social roles” can be treated as empty signifiers, that is “significant elements without a signified element, elements of a system that does not have content” (Laclau, 2004, p. 67). It is because the signifiers, i.e., the mentioned terms, are always open to new meanings and are filled with them in the course of endless discourses. As a result, we believe we know what, for example, impairment, disability or normality is. However, our common understandings are the subject of endless struggles over the essence and meaning of these terms. Thus, there is no one universal definition of disability, as it changes over time and may have a different meaning for anyone. Consequently, disability may not only be understood differently in different cultures but also differently by members of the same culture.

The third assumption of the cultural model of disability boils down to the thesis that disability does not mean a feature of an individual but a category of

⁹ The concept of discourse proposed by Ernst Laclau and Chantal Mouffe (2007) can, in some simplification, be understood as a discussion; that is, an exchange of opinions through written and spoken messages. In other words, this term refers to the use of language for the purpose of communicating on a specific topic in a specific area of life.

human differentiation, which can be embodied¹⁰ and thus materialised. The term “disability” is assigned to such bodily changes in an individual which can be observed. It is also used to mark changes in human organisms that are not visible to outside observers, for example, heart disease, cancer, diabetes, rheumatic disease, and cognitive or emotional disorders. Both visible and invisible changes in the body are interpreted within dichotomous body differences: healthy – sick, no deficits – with deficits, normal – abnormal. According to the representatives of the cultural model, disability “exists only when certain differences (bodily and embodied) can be distinguished and considered ‘essential for health’ within a given cultural and historical state of knowledge” (Waldschmidt, 2017, p. 25). Disability is not an original fact but a naturalised difference. Congenital deafness, i.e., a body deficit, is an example illustrating the position presented. In this situation, the child usually gets cochlear implants. However, in the culture of the deaf, the inability to hear is treated as a cultural difference and a source of special linguistic competence, which is sign language. According to the cultural model, hearing impairment is treated as a seemingly real disability.

The next, fourth assumption of the cultural model indicates the need to reverse the current epistemological perspective in the approach to disability issues. Namely, the commonly unquestionable “efficiency” usually referred to as “normality” should be questioned. Representatives of the cultural model of disability believe that focusing on the “other side of the coin”, that is – normality, enables fuller insight into postmodern societies and the changes taking place in their cultures. Instead of just “looking” at people with disabilities and asking what problems they are struggling with and what support from the society they need, the current perspective should be broadened and include the entire society and its culture. For example, the question is: why are some differences regarded as natural manifestations of human heterogeneity and others as symptoms of disability? Why is there a need in societies to classify people as “fit” and “disabled”? Why is disability assessed negatively? How is otherness constructed and reconstructed in different societies and cultures? It is also necessary to reflect on: how in a given culture “knowledge of the body is created, modified and transmitted; which norms and disorders are socially constructed and how; how exclusive and inclusive practices are created in the day-to-day running of different institutions; how in a given culture the subjectivities and identities of its participants arise and develop” (Waldschmidt, 2018, p. 76). Changing the epistemological perspective

¹⁰ It is about being a symbol or an expression of something. This is a clear reference to cognitive science, in which the body (and especially the brain) is treated as a major factor in shaping the mind.

requires representatives of social sciences to adopt a new approach to the issue of disability. This issue can no longer be treated as a secondary issue but one of the key issues if researchers want to get a complete picture of a given society and its culture.

ADVANTAGES OF THE CULTURAL MODEL OF DISABILITY

The cultural model extends the existing understanding of the essence of disability not only in theoretical but also in practical dimensions. This thesis can be substantiated by the example of Article 19 of the United Nations Convention on the Rights of Persons with Disabilities, according to which people with disabilities have the right to live independently and be included in society. In order to understand the benefits offered by the cultural model, it is necessary to consider how it relates to the issue of independent living compared to the two existing models, i.e., medical and social models (Waldschmidt, 2018). Supporters of the medical model will wonder if people with disabilities really want to decide about themselves and if they can live independently at all. Representatives of the social model will focus on analysing what barriers in society prevent people with disabilities from living independently and how these barriers should be eliminated. Representatives of the cultural model “will strive to understand how in a given culture and society, personal autonomy and independent life are understood, what discourses are related to these concepts, and what is the genealogy of these discourses” (Waldschmidt, 2018, p. 77). The positions of individual models regarding the impact of the right to personal autonomy on the real life of the disabled, are also different. Representatives of the medical model ask how existing institutions increase the ability of their disabled residents or clients to enable self-determination. Supporters of the social model analyse whether Article 19 of the Convention has caused noticeable effects on society and the self-determination of people with disabilities. Whereas representatives of the cultural model consider the interdependence of able-bodied and disabled people in everyday life, and determine the actual consequences of this interdependence for the autonomy of both. Next, everyone in the disability models has different proposals for the practical implementation of the principle of independent living, for example, through social services. In the medical model, the primary question is whether specialists can support people with disabilities in their efforts to live independently, and what forms of support they can offer. Supporters of the social model consider whether the existing forms of assistance and solutions related to the accessibility of the social environment enable people

with disabilities to live independently. Whereas, in the cultural model, promoting a more general approach, the questions of why in modern societies personal autonomy is so important; what normative expectations and limitations are associated with it, arise.

The considerations on independent living allow us to indicate the main advantage of the cultural model of disability. Namely, it does not reject earlier models, but it enriches them (Titchkosky, 2007). Generally speaking, it can be said that the medical model is conducive to the provision of services for people with disabilities, the social model contributes to the emancipation of these people, and the cultural model “offers an additional and at the same time a broader perspective, and encourages both historicising, generalising and theorising of the studied issues” (Waldschmidt, 2018, pp. 77–78). Undoubtedly, analysing and solving problems related to disability, taking into account the cultural perspective, requires the involvement of the representatives of various disciplines in social sciences and humanities. The concept of interdisciplinary teams, whose members exchange information from the scientific discipline they represent to solve a specific problem, is insufficient. A transdisciplinary approach is necessary, which is an unquestionable advantage of the cultural model, as it offers a legitimate hope for a comprehensive and detailed study of the phenomenon of disability¹¹. Consequently, it will be possible to solve many practical problems, for example, developing a coherent theoretical basis for inclusive education.

The cultural model of disability is a useful analytical tool in research on disability culture¹², especially in studying the relationship between the culture of disability and the dominant culture. It is evidenced by the fact that the cultural model of disability is gaining more and more acceptance in the environment of disabled people, especially the deaf (Holcomb, 2013). However, it is not about treating the relationship between representatives of the disabled minority and the efficient majority in terms of cultural adjustment in various areas of joint functioning, such as science, art, family, and work – as proposed by Rafał Dziurla (2018). According to this author, two directions of cultural adjustment can be distinguished. The first

11 The transdisciplinary research team consists of representatives of various scientific disciplines who work together to solve problems that they would not be able to solve within their own disciplines. Transdisciplinary means “what is between various scientific disciplines is within them, and is beyond each of them” (Urbanowicz, 2012, p. 454).

12 Steven Brown defined the disability culture as follows: “People with disabilities form a kind of group identity. We have a common history of oppression and a common experience of resisting oppression. We create art, music, literature and other forms of our life – our culture inspired by our experience and disability. Most of all, however, we are proud of ourselves as people with disabilities. We recognize our disability as a part of our identity” (Brown, 2003, pp. 80-81).

is that the majority culture “creates the conditions that make it possible to best match one’s own values and practices with the values and practices relevant to the minority culture”. The second, on the other hand, “requires that the practices and values of the minority culture be adjusted to the practices and values of the majority culture (Dziurla, 2018, p. 94). It is difficult to agree with such a position because “fitting” may initiate the process of assimilation of the culture of disabled people to the dominant culture and, consequently, subordinate these people to the dominant culture against their will. It is a much better solution for both the efficient majority and the disabled minority to develop common solutions while maintaining and respecting cultural differences between them without assuming that one of the parties is to adapt to the other. Two examples of cooperation to develop the best forms of coexistence of majority and minority cultures can be found in the work of Patric Devlieger (2005). In the first example, the task of the group of architects and blind and visually impaired people was to discuss how they perceive public and private facilities and how they use them. It turned out that the architects gained a complete insight into the perspective of the disabled interlocutors. In the second example, people with various disabilities first identified places and facilities they would like to use more often, then attended to them, talking to their owners and managers. During the talks, they indicated what changes and improvements in the physical environment of these places would be beneficial for them. Within six months, the owners and managers of one-third of the places introduced the proposals. The emic character¹³ is an unquestionable advantage of the presented methods of developing a cultural coexistence of an efficient majority and a disabled minority.

CONCLUSION

Using the language of theory by Thomas Kuhn (2011), it can be said that the medical model was the classic disability paradigm¹⁴. However, over time, thanks to the activity of disabled people fighting for their rights, there was a paradigm

13 In research on culture, one can adopt one of the two perspectives: internal (emic), i.e., looking at the phenomenon from the perspective of the studies persons, or external (etic), i.e., presenting the phenomenon from the researcher’s perspective. Thus, the emic approach assumes examining the system of culture from within – through direct contact with the subjects, and striving to understand the behavior of these people in accordance with their own reference systems.

14 According to Thomas Kuhn, a paradigm is the system of thought generally accepted by the scientific community, containing: the most general assumptions and conceptual models, theories established facts as well as problems that are raised in the research, and typical techniques by

shift. A social model of disability, often referred to as the “big idea”, emerged and became the groundwork of disability studies (Disability Studies) – a new, interdisciplinary field of research rooted in the social sciences, humanities and knowledge of rehabilitation. It seems that now is the time for another paradigmatic shift, namely, the cultural model of disability. At the same time, it should be strongly emphasised that the transition to the new paradigm does not mean abandoning the previous ones. “After all, in physics, the replacement of Newtonian mechanics with Einstein’s theory of relativity did not invalidate the previous approach, but only showed its limitations” (Twardowski, 2019, p. 22). The existing achievements of the social model undoubtedly allow for a better understanding of the phenomenon of disability and its determinants. However, the postulate of building a model that would integrate all its dimensions: bodily, psychological, cultural, social and political, remains present. Undoubtedly, the cultural model of disability, still being developed, can be considered the right direction in achieving this goal.

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which these problems are solved. The paradigm is developed in the course of many years of reliable research and adopted on the basis of consensus (Kuhn, 2011).

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