

Nutritional care is a human right: Translating principles to clinical practice

Diana Cárdenas ^{a, *}, Maria Isabel Toulson Davisson Correia ^b, Gil Hardy ^c, Juan B. Ochoa ^d, Albert Barrocas ^e, Régis Hankard ^f, Isabelle Hannequart ^g, Stéphane Schneider ^h, Charles Bermúdez ⁱ, Karin Papapietro ^j, Teresa Pounds ^k, Cristina Cuerda ¹, Winai Ungpinitpong ^m, Anna–Lena du Toit ⁿ, Rocco Barazzoni ^o

^a Faculty of Medicine, Research Institute on Nutrition, Genetics and Metabolism, El Bosque University, Bogotá, Colombia

^b Surgical Department, Medical School, Universidade Federal de Medicina, Belo Horizonte, Brazil

^g Université de Tours, Tours, France

^h Nutrition Support Unit, Gastroenterology and Nutrition Department, Archet University Hospital, Nice, France

ⁱ Surgery and Nutrition Department, Clínica La Colina and Clínica Del Country, Bogota, Colombia

^j Nutrition Unit, Hospital Clínico de La Universidad de Chile, Santiago, Chile

^k Department of Pharmacy, Wellstar Atlanta Medical Center, Atlanta, Georgia, USA

¹ Nutrition Unit, Hospital General Universitario Gregorio Marañón, Facultad de Medicina, Universidad Complutense, Madrid, Spain

^m Surgery Department, Surin Hospital, Thailand

ⁿ Groote Schuur Hospital, Cape Town, South Africa

^o Department of Medical, Technological and Translational Sciences, University of Trieste, Ospedale di Cattinara, Trieste, Italy

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SUMMARY

We have previously advocated that nutritional care be raised to the level of a human right in a close relationship to two well recognized fundamental rights: the right to food and the right to health. This paper aims to analyze the implication of nutritional care as a human right for healthcare practitioners. We will focus on the impact of the Human Rights Basic Approach (HRBA) on health care professionals (HCPs), namely how they can translate HRBA into routine clinical practice. Ethics and human rights are guiding values for clinical nutrition practitioners. Together they ensure a patient-centered approach, where the needs and rights of the patients are of the most significant importance. Human rights are based on the powerful idea of equal dignity for all people while expressing a set of core values, including fairness, respect, equality, dignity, and autonomy (FREDA). Through the analysis of FREDA principles, we have provided the elements to understand human rights and how a HRBA can support clinicians in the decision-making process. Clinical practice guidelines in clinical nutrition should incorporate disease-specific ethical issues and the HRBA.

The HRBA should contribute to build conditions for HCPs to provide optimal and timely nutritional care. Nutritional care must be exercised by HCPs with due respect for several fundamental ethical values: attentiveness, responsibility competence, responsiveness, and solidarity.

Abbreviations: HRBA, Human Rights Basic Approach; HCP, Healthcare professionals; DRM, Disease-related malnutrition.

* Corresponding author. Universidad El Bosque, Carrera 7 No. 117 – 15, Bogota, Colombia.

^c Ipanema Research Trust, Auckland, New Zealand

^d Critical Care Medicine, Hunterdon Medical Center, New Jersey, USA

^e Tulane School of Medicine New Orleans, Louisiana, USA

^f Nutrition Mobile Unit, CHU Tours, Université de Tours, European Institute for History and Culture of Food, University of Tours, France

E-mail addresses: dianacardenasbraz@gmail.com (D. Cárdenas), isabel_correia@uol.com.br (M.I. Toulson Davisson Correia), gil.hardy50@gmail.com (G. Hardy), jbochoa@ newspringhouse.com (J.B. Ochoa), abarroc@tulane.edu (A. Barrocas), regis.hankard@inserm.fr (R. Hankard), isabelle.hannequart@univ-tours.fr (I. Hannequart), schneider.s@ chu-nice.fr (S. Schneider), chebermud@yahoo.com (C. Bermúdez), kpapapie@gmail.com (K. Papapietro), teresapounds@yahoo.com (T. Pounds), cuerda.cristina@gmail.com (C. Cuerda), winai.ung@gmail.com (W. Ungpinitpong), Anna-Lena.duToit@westerncape.gov.za (A. du Toit), barazzon@units.it (R. Barazzoni).

1. Introduction

Nutritional care is a process that involves distinct, interrelated steps that should be provided in a systematic sequence [1]. The aim is to deliver comprehensive nutritional care to all patients, with particular attention to the prevention or treatment of patients with disease-related malnutrition (DRM) [2-4]. The ultimate objective of nutritional intervention is that through the provision of evidence-based nutrition interventions positively impact clinical outcomes including enhanced survival. Despite this, nutritional care in hospitals and after hospital discharge, is frequently insufficiently implemented and is not generally part of the patient's holistic care [5,6]. Among the cited reasons for the underimplementation of nutritional care are the lack of malnutrition awareness, poor education of healthcare professionals (HCPs), (including physicians) [7–11], the lack of reimbursement of nutrition treatments, and the lack of a relevant public health policy [12,13]. DRM and nutritional care are issues largely unknown among policymakers [13] and are generally not found on national or global health policy agendas.

As we have previously advocated, nutritional care was raised to the level of a human right in a close relationship to two well recognized fundamental rights: the right to food and the right to health [14,15]. That would mean that all patients have access to "beneficiate from the right to be screened and diagnosed for disease related malnutrition, to receive regular hospital diet, therapeutic diet (i.e. food modification and supplements) and evidencebased medical nutrition therapy (i.e. Artificially Administered Nutrition and Hydration, AANH) administrated by an interdisciplinary team of experts, and the government has the duty to guarantee" [14,16]. This approach defines specific duty bearers as the states, policymakers, institutional managers, and HCPs.

In this article we will analyze the implication of nutritional care as a human right and will focus on the impact of HRBA on clinicians and HCPs, particularly on how this approach can support clinicians in the decision-making process. We aim to provide the elements to understand human rights and how a HRBA can support clinicians to make evidence-based decisions in the best interests of their patient.

2. Why do we need a human rights-based approach in clinical nutrition?

Human rights are moral principles considered as norms that aim to protect people from social and political abuse [17]. Human Rights were first defined in the Universal Declaration of Human Rights adopted in 1948 as a response to the Holocaust atrocities. Human rights principles are for every human being (universal), independent of other factors such as religion, ethnicity, or nationality. Everyone should have access to human rights simply because they are human beings. No one's human rights can be limited or restricted in any circumstances. Such principle refers to how the state (public authorities) must treat everyone. The HRBA provides a practical framework to protect the rights of everyone.

The link between the HRBA and HCPs is bi-directional [18,19]. According to Curtice et al. "Ignoring or violating human rights has a detrimental effect on people's health and, conversely, using a HRBA can improve health outcomes and deliver better quality personcentered healthcare" [20]. Thus, according to the United Nations, a HRBA seeks to deepen understanding of the relationships between rights-holders and duty-bearers contributing to bridge the gaps between them.

The imperative for applying this approach in the context of clinical nutrition is that HRBA has significant implications to the way priorities and objectives are identified and program outcomes are formulated [14]. Moreover, this approach reinforces situation analysis at three levels:

- 1. "Causality analysis: drawing attention to root causes, for example the origin of DRM and any lack of patient's nutritional care access;
- 2. Role or obligation analysis: helping to define who owes what obligations to whom, especially with regard to the identified root causes;
- Intervention analysis identifying the interventions needed to build rights-holders' capacities and improve duty-bearers' performance".

Human Rights can be articulated to a set of core values including fairness, respect, equality, dignity and autonomy (FREDA). Thus, we need a HRBA in clinical nutrition because this could guarantee that human rights principles, values, and standards are made real in clinical practice.

3. Building human rights into clinical practice frameworks

HRBA is the approach by which human rights can be protected in clinical and organizational practice by adherence to the FREDA principles [20]. The usefulness of these principles is that they form the basics of good clinical care that should be integrated into what clinicians already do on a daily basis. It is important to highlight that these principles "are used to inform decisions, not to determine them", and that the five FREDA principles are interdependent and should not be considered separately [20]. They may often overlap but should be considered together. This means that in any particular situation, all five principles must be considered, but the weight given to each principle in reaching a particular conclusion can vary, and will depend on the issues under consideration.

For the purpose of this paper, we have applied the five FREDA principles, considered to underpin all international human rights treaties. In Table 1 and Table 2 we provide a brief explanation of each of the FREDA principles, reference the relevant article(s) from the European Convention on Human Rights (ECHR) Act 2003 that are most relevant to that principle, and we provide examples of how these values can be promoted and incorporated into clinical nutrition practice (Fig. 1).

4. Ethical approach to nutritional care as a human right

Ethics is concerned with principles that allow us to make decisions about what is right and wrong. HCPs have the ethical duty to assure optimal and timely nutritional care within the boundaries of resources provided for them [21,22]. This obligation must be exercised with due respect to a number of fundamental ethical values. Thus, ethics and human rights are guiding values for clinical nutrition practitioners. Together they ensure a patient-centered approach, in which the needs and rights of the patients are of the greatest importance [23]. Health care professionals must be competent in medical ethics that govern their practice and understand the link between clinical nutrition and the human rights of their patients.

When it comes to analyze the impact of an ethical approach to the practice of clinical nutrition it should be emphasized that nutrition as an ethical subject is able to present itself as a legitimate form of care in medical practice, since life without food is not

Table 1

Definition of the FREDA human rights core values proposed for a HRBA to Clinical Nutrition supported by article(s) from the European Convention on Human Rights (ECHR) most relevant to each FREDA principle [15].

Core values	Definition	Article(s) from the ECHR
Fairness:	"Ensuring that when a decision is made with a person using a service about their care and support, the person's views are sought, listened to and weighed alongside other factors relevant to the decision. If a decision interferes with a person's human rights, this must be legally justified, proportionate and only when all other alternatives have been considered. Together with equality and autonomy they ensure that the decision-making process is free from discrimination and that the person is involved in the decision-making process" (15).	Art 14- Prohibition of discrimination
Respect:	Respect is the "objective, unbiased consideration and regard for the rights, values, beliefs and property of other people". Respect applies to the person as well as their value systems. Respect is central to providing person-centered care and support. People who use services must be listened to, and what is important to them must be viewed as important to the service. The principle of respect must be upheld regardless of a person's impairment or loss of capacity. Upholding the principle of respect also means that another person nominated by the person themselves, such as a family member or friend, is valued and listened to."	Article 8 — the right to respect for family and private life; Article 9 — the right to freedom of thought, conscience and religion;
Equality/equity:	Equality means people having equal opportunities of access and of being treated no less favourably than other people on the grounds set out in legislation. These grounds include: sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or any other status. Equity means everyone is provided based on the individual needs and available resources.	Article 14- prohibition of discrimination.
Dignity:	Dignity means treating people ethically and to be valued and respected for their own sake, and in a way that values them as human beings and supports their self-respect, even if their wishes are not known at the time. Dignity is the core value of human rights. Lack of dignity is a common theme in examples of abuse and neglect in health care settings including malnutrition.	Article 3 — prohibition of torture; Article 8 — the right to respect for family and private life
Autonomy	Implies the principle of self-determination. This means that a patient is allowed to make free choices. The decision should be based on clear, sufficient and relevant information. Patients should participate in decision-making. Respecting and supporting autonomy is important in health care as it is a fundamental aspect of person- centred care. In a health care setting, people may require different levels of support to assert their autonomy and make their own decisions. This means health care professionals have a key role in this process. The ability to be autonomous, and make decisions, can and must be supported and developed.	Article 5 — the right to liberty and security; Article 8 — the right to respect for family and private life.

possible [24]. Feeding patients becomes a form of treatment, raising new ethical issues when applied to specific situations.

The relevant question here is which ethical characteristics are fundamental to clinical practice. In other words, to know how healthcare professionals should act when feeding sick patients. What is the best way to care for one specific patient at a specific time?

5. Nutritional care process and the phases of care

The ethics of care is a normative theory that places the phenomenon of care at the center of ethical reflection [25]. It is based on the understanding of the human being as a vulnerable and interdependent relational being. While traditional moral theories (i.e., utilitarianism, deontology, theory of justice, virtue ethics) are based on the primacy of autonomy, the ethics of care, which is more context-based and concrete, emphasizes the notion of vulnerability, which it considers to be one of the essential characteristics of the human condition. The ethics of care emphasizes the importance of response, thus, the ethical question is «how to respond? » [25] (see Fig. 2).

The ethics of care defined by Tronto as a "practice and a disposition" is an ongoing process consisting of five phases of caring and five moral characteristics of care [25]. Those moral elements are specific attitudes and skills necessary for effective caring. This normative theory is useful to define some ethical characteristics necessary for good nutritional care and is a useful tool that can help address key questions regarding a HRBA. Thus, the phases of care can correspond to the seven steps of the nutritional care process as proposed in Fig. 2.

According to the ESPEN guidelines on definitions and terminology of clinical nutrition, nutritional care should be provided in a systematic sequence that involves seven distinct interrelated steps, and this systematic sequence is called the nutritional care process [1].

The first and second steps are malnutrition risk screening and nutritional assessment, which can be conceived as the "caring about" phase of care ethics. This first phase requires an ethical element, that of attentiveness, namely a "just and affectionate regard to an individual reality". In a practical way, this means that the healthcare professionals identify the need for nutritional care by identifying subjects who are at-risk of malnutrition or are already malnourished, by using an appropriate validated tool in all subjects that come in contact with healthcare services, and by assessing the patient's nutritional status [21,24].

Caring about malnutrition leads to the establishment of an appropriate response which is consolidated in the "taking care of" phase. In this phase, the healthcare professionals recognize their responsibility to respond to a patient's risk of malnutrition or to any degree of malnutrition and reach a diagnosis. This responsibility is shared, and concerns all those involved in patient care. The healthcare professional, by making a nutritional plan, will ensure to meet all the necessary nutritional requirements of the patient. In this phase, actions have mainly two specific purposes: 1. To combat malnutrition or 2. To limit loss of quality of life through nutritional therapy. It is worth noting that responsibility is ethics-based and must not be conceived as an duty-based responsibility [21,24].

The third phase of the ethics of care is the "caregiving", which implies the direct activity of contact with the patient. The healthcare professionals should be able to respond in the best way to the nutritional needs of the patient, by providing nutrients orally, via enteral tube-feeding or parenteral nutrition, to prevent or treat malnutrition in an individualized way. In this phase, competence is considered an ethical element. One cannot simply acknowledge the need to care and accept the responsibility, but follow through without enough competence or adequate skill. Prescribing nutrition interventions in patients requires far more than providing for the food that the patient cannot or will not eat; it requires training and understanding of the personalized nutritional requirements in a given patient during her/his illness like any other area of medical care, lack of competence would result in the needs of care not being met or in an increase in the risk of complications. Thus, healthcare professionals must commit to

Core value	How to promote each FREDA value in the day-to-day work of clinical nutrition practice
Fairness	Providing relevant information
	• Ensure patients have sufficient information on nutritional care to make independent and informed choices (patient empowerment).
	Seeking consent
	 Explain the risks and benefits of proposed nutritional therapy options. Ensure that individuals knows they have a choice and that can consent freely without pressure.
	 If needed, consult with the health care representative or family to know the persons' preferences.
	Protecting personal information
	Recognize confidentiality in treating the patient's information.
	Supporting a person to make an advance health directive (AHD)
	• Explain and allow the person to decide on their AHD regarding the role of nutrition and survival
	 Participating in decisions Recognize that the patients are given the opportunity to be heard and to participate in decision-making (patient empowerment)
Respect	Day-to-day communication
	• Ensure that the person has all the available information necessary to decide about nutritional care, in a way they understand (patient
	empowerment).
	 When providing information to a person, consider their preferences and their background, for example previous life experience, education
	attainment, literacy, culture and religious beliefs.Take the time to listen to individuals, and to understand them as an individual without judgement.
	 Avoid using technical language to describe the person's condition or care. Instead, use the persons' own words and terms they can understand
	Person-centered planning
	• Respect the persons as the expert on their own life and support them to lead the development of person-centred plan as much as possible.
	• Ensure the person-centered plan reflects the goals that are unique to the persons and that are meaningful to them
	• A person's goals should not be dependent on available resources.
	 Ensure that nutrition care plan focuses on what is important to a person, and how the person wants to live (patient empowerment). Supporting the achievement of human rights
	Promote the person's right to nutritional care access.
	Where applicable, support individuals to realise all theirs rights including the right to the whole process of nutritional care.
quality/equity	Providing quality nutrition care for all
	Support people who use your service to get nutritional care they need regardless of sex, race, color, language, religion, political or other opinio
	national or social origin, association with a national minority, property, birth or any other status.
	 The quality of nutrition care that is provided is the same for everyone. Presuming and supporting capacity
	 Recognise that you must always presume that a person has capacity and that you should never judge a person's decision-making ability based of
	sex, race, color, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or ar
	other status.
	Recognise that you cannot presume that a person lacks capacity in relation to a certain matter or decision on the basis that they makes a decisio
	that seems unwise to you.
	 Encouraging equality and a human rights-friendly service Recognise the importance of there being a culture of equality within your service where all people achieve equal access to and equal outcome
	from nutritional care.
	• Be aware that there should be no blanket policies, conditions or rules in place in your service that can impact people's human rights.
Dignity	Meeting basic nutritional need
	• Ensure that people have access to appropriate nutrition and hydration so that they do not suffer from malnutrition or dehydration.
	 Ensure that every patient has access to regular hospital diet, therapeutic diet, and evidence-based medical nutrition therapy (including AANH provided by HCPs.
	 Ensure that evidence-based medical nutrition therapy (including AANH) does not cause harm.
	 Do not leave the patient on unnecessary fasting.
	Maintaining privacy
	 Avoid rushing a task in a way that might impact the patient's privacy and dignity.
	Communicating effectively
utonomy	• Ensure that a person's dignity is maintained even if the person is unconscious, and unable to communicate.
Autonomy	 Seeking consent Make sure that you communicate clearly and effectively with the patient.
	• Use language or other means of communication that people can understand and do not use medical or social care jargon to discuss nutritional ca
	issue.
	• Make sure that the person is provided with complete and relevant information about nutritional care options, including the advantages ar
	disadvantages of each option, to ensure people can make a fully informed decision.
	 Openly discuss risk management in a positive and proactive manner Understanding and respecting a person's will and preferences
	 Make sure that you understand the will and preferences of the patient to ensure that you can promote and support people's autonomy whe
	assisting in or supporting their decision-making process.
	 In order to make sure that autonomy is upheld, support a person's choice in relation to care and support regardless of whether or not you believe
	is the right decision.
	Supporting capacity and responding accordingly
	 If a person has been assessed as lacking capacity in relation to a particular matter or decision, make every effort possible to ensure that the person
	past and present will, and preferences have been determined.This includes considering the views of any person named by the person themselves, whether a family member, a friend, surrogate, or independent
	 This includes considering the views of any person named by the person themselves, whether a family member, a mend, surrogate, of independent advocate, and consider any written documentation (such as an AHD) and ensure that any decision made takes these into account.
	 Although a person might have been assessed as not having capacity to make a decision at a particular moment in time, understand that when it
	relation and possible for you to do so you should make our that the person's conspirity is reviewed and that shapees are made accordingly.

Although a person might have been assessed as not having capacity to make a decision at a particular moment in time, understand that when it relevant and possible for you to do so, you should make sure that the person's capacity is reviewed and that changes are made accordingly.

How HCPs can apply the FREDA principles in their daily practice ?

F airness	 Providing relevant information Seeking consent Protecting personal information Supporting a person to make an advance health directive Participating in decisions 	
R espect	 Day-to-day communication Person-centred planning Supporting the achievement of human rights 	N CON
Equity	 Providing quality nutrition care for all Presuming and supporting capacity Encouraging equality and a human rights-friendly service 	R
D ignity	 Meeting basic nutritional need Maintaining privacy Communicating effectively 	Nutritional care is a human right
A utonomy	 Seeking consent Understanding and respecting a person's will and preferent Supporting capacity and responding accordingly 	nces

Fig. 1. Actions that a clinician can apply in daily clinical practice in order to respect de 5 FREDA principles.

life-long learning to ensure competence in nutritional care practice [21,24].

In phase four "care receiving", healthcare professionals assess the success of nutritional therapy with the patient and document this process. This phase is essential to preserve the relationship between patients and healthcare professionals. The ethical element in this phase is responsiveness, which refers to the receiver's responsiveness to the nutritional care. This means the way the patient or the family/caregiver perceive the care [21,24].

According to the ethics of care, the realization of a complete nutritional care process by the healthcare professional means they are responding to the vulnerability of the patient. Finally, the fifth phase is "caring with", which highlights the role of institutions in the organizational structures for providing nutritional care. The ethical element in this phase is solidarity and support.

The ethics of care highlights two key considerations [26]. First, the care concerns a human being who is suffering from a pathological condition that we are able to treat or prevent. Second, when we take care of someone, this it means that we care about the emotional, social and psychological dimensions. Consequently, care is not only a matter of supplying a treatment in order to alleviate or to cure but is also a matter of humanity. In that sense, nutritional therapy, as a medical therapy, is capable (most of the time) to cure or prevent malnutrition and help recover from disease but it is also

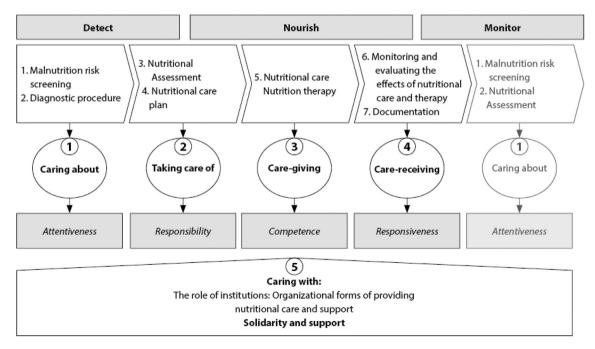


Fig. 2. The five phases of ethics (bold) of care and their five ethical elements (italics) are integrated to the nutritional care process (as defined by Cederholm T. et al. [1,21]).

supporting basic nutrient feeding which is essential to survival. This approach also implies that ethically, the best decision for the patient must be taken and this may include, under certain circumstances, the decision not to feed (i.e in the case where nutrition is considered a futile therapy). In the latter context, any technological or legal obstacles to the application of ethical decisions should be anticipated if possible and resolved [21].

The ethical and human rights-based approaches should be reflected in clinical nutrition practice guidelines. Clinical practice guidelines in clinical nutrition should incorporate disease-specific ethical issues and the human rights approach.

6. Conclusion

Human rights are about people being treated with fairness, respect, equality and dignity, and clinicians should incorporate it into their clinical practice. By recognizing vulnerability of the patient in particular regarding the nutritional status, promoting equality and ensuring human rights helps to make sure that all patients using health care services receive good quality nutritional care. The human rights norms and ethical values and principles can contribute to moving forward in promoting patient's access to appropriate nutritional care.

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Authorship statement

Diana Cardenas, Maria Isabel Toulson Davisson Correia, Gil Hardy and Rocco Barazzoni equally contributed to the conception, design of the research and drafted the manuscript; Juan B. Ochoa, Charles Bermúdez, Karin Papapietro, Régis Hankard, Isabelle Hannequart, Anna-Lena du Toit, Albert Barrocas, Stephane Schneider, Teresa Pounds, Winai Ungpinitpong and Cristina Cuerda contributed to the contributed to the interpretation of the data. All authors critically revised the manuscript, agree to be fully accountable for ensuring the integrity and accuracy of the work, and read and approved the final manuscript.

Conflict of interest

Diana Cardenas: none; Maria Isabel Toulson Davisson Correia: Lecturer for Abbott, Baxter, Danone, Fresenius, Nestlé, Takeda; Juan B Ochoa: Lecturer for Nestle Health Science, Fresenius Kabi and a past Chief Medical Officer until July 1, 2018 - Nestle Health Science North America; Albert Barrocas: None; Gil Hardy: none; Charles Bermúdez: Abbott, Baxter, Fresenius, Nestlé, Amarey, Bbraun, Fenavi, Eurociencia, Takeda; Karin Papapietro: Lecturer for Fresenius; Régis Hankard: none; Anna–Lena du Toit: none; Teresa Pounds: none; Winai Ungpinitpong: none; Cristina Cuerda: Lecturer for Abbott, Baxter, Fresenius, Nestle, Nutricia, Persan, Takeda: Isabelle Hannequart: none; Stephane Schneider[:] none; Rocco Barazzoni: none.

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