Clinical nutrition and human rights. An international position paper

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SUMMARY

The International Working Group for Patients’ Right to Nutritional Care presents its position paper regarding nutritional care as a human right intrinsically linked to the right to food and the right to health. All people should have access to food and evidence-based medical nutrition therapy including artificial nutrition and hydration. In this regard, the hospitalized malnourished ill should mandatorily have access to screening, diagnosis, nutritional assessment, with optimal and timely nutritional therapy in order to overcome malnutrition associated morbidity and mortality, while reducing the rates of disease-related malnutrition. This right does not imply there is an obligation to feed all patients at any stage of life and at any cost. On the contrary, this right implies, from an ethical point of view, that the best decision for the patient must be taken and this may include, under certain circumstances, the decision not to feed. Application of the human rights-based approach to the field of clinical nutrition will contribute to the construction of a moral, political and legal focus to the concept of nutritional care. Moreover, it will be the cornerstone to the rationale of political and legal instruments in the field of clinical nutrition.

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Abbreviations: AIDS, Acquired immunodeficiency syndrome; AANH, Artificially administered nutrition and hydration; ASPEN, American Society for Enteral and Parenteral Nutrition; CESCR, Committee on Economic, Social and Cultural Rights; DOHaD, Developmental origins of health and disease; DRM, Disease-related malnutrition; ESPEN, European Society for Clinical Nutrition and Metabolism; FELANPE, Latin American Federation of Nutritional Therapy, Clinical Nutrition and Metabolism; HIV, Human immunodeficiency virus; HRBA, The human rights-based approach; ICESCR, International Covenant on Economic, Social and Cultural Rights; PENSA, Parenteral and Enteral Nutrition; PENS, Parenteral and Enteral Nutrition Society of Asia; UN, United Nations; WASPEN, West African Society of Parenteral and Enteral Nutrition.

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1. Introduction

Malnutrition (i.e. undernutrition, inadequate vitamins or minerals, overweight and obesity) is a major contributor to disease burden and thus, the delivery of optimal nutritional care should be an effective strategy to reduce its global burden [1,2]. The situation is even more acute in children, not only because neglecting malnutrition makes health professionals accountable for an actual threat to the child, but also for the future adult she/he will become. In childbearing women and children, malnutrition is a strong determinant of health in adulthood. This is the concept of the “early origin of adult” or “developmental origins of health and disease” (DOHaD) or “fetal programming/developmental programming”. In these situations, malnutrition has long lasting effects with potential impacts on the health of future generations [3,4]. The positive impact of nutritional care is related to its capacity to influence disease outcomes, particularly the vulnerable malnourished population [5–8]. Indeed, nutritional care contributes to reduced morbidity, mortality, length of hospital stay as well as fewer readmissions. Therefore, it is considered cost effective, and may influence the financial sustainability of health care systems [9–13].

Nutritional care is “an overarching term to describe the form of nutrition, nutrient delivery and the system of education that is required for meal service or to treat any nutrition-related condition in both preventative nutrition and clinical nutrition” [14]. In the clinical context, nutritional care should be understood as a process, which is carried out by interrelated steps including screening, diagnosis, assessment, nutritional therapy and monitoring [14,15]. It aims to early assess, prevent and treat malnutrition by implementing an optimal nutritional therapy strategy.

The efficacy of nutritional care has been extensively documented, however, high levels of disease-related malnutrition (DRM) have persisted in all health care settings over the past five decades despite marked advances in medical sciences over this same period [11,16–21]. Moreover, public policies and legislation to address this issue are scarce and the human rights approach has never been assessed.

Academic, practical, social and economic factors have been recognized as barriers to the improvement of nutritional care in clinical nutrition, and they must be addressed [22]. In the last decades, different strategies have emerged to address these issues and overcome these barriers. In Europe, the Resolution ResAP (2003) on food and nutritional care in hospitals addressed this problem and was approved by the Council of Europe in 2003 [23]. In the US, The Alliance to Advance Patient Nutrition gathered key US scientific nutrition companies, in 2013, to advocate for effective nutrition care, including optimal food intake [24]. In Latin America, this problem was addressed by the International Declaration on the Right to Nutritional Care and the Fight Against Malnutrition, named the Cartagena Declaration, signed in May 2019 [25]. Among these initiatives, human rights can be identified as a common basic foundation.

Indeed, it is well known that there is an inextricable link between human rights and health. According to Dr. Jonathan Mann, “Health and human rights are complementary approaches for defining and advancing human well-being. The goal of linking health and human rights is to contribute to advancing human well-being beyond what could be achieved through an isolated health or human rights-based approach” [26]. Despite the evident rapport, clinical nutrition has never been examined under such perspective. This is why an international working group was launched in 2020 to explore how the human rights-based approach can contribute to the challenges faced by the practice of clinical nutrition in increasingly demanding health care systems. The working group is composed of experts in clinical nutrition and representatives of ASPEN, ESPEN, FELANPE, PENSA and WASPEN. Therefore, the aim of this position paper is to provide the link between clinical nutrition and human rights, in an attempt to characterize nutritional care as a human right, and thus highlight the need to early diagnosis and treatment of DRM as a holistic process of patient care.

2. The human rights-based approach

The human rights-based approach (HRBA) is a conceptual framework that can be applied to clinical nutrition. According to the United Nations (UN), this approach is “normatively based on international human rights standards and operationally directed to promoting and protecting human rights” [27]. Applied to the healthcare context, this approach focuses “on the underlying social determinants of health and on emphasizing the principles of accountability, meaningful participation, transparency, equality and non-discrimination” [28]. Priorities and objectives in the field of clinical nutrition can be identified and program outcomes can be formulated, through this approach. It is an interesting approach in the current analysis as it reinforces a situation evaluation on three levels: 1 – the causality analysis: to focus attention on root causes, in our case, analysis of the origin of DRM; 2 – the role or obligation analysis: to help define who owes which obligations to whom, in our case, identification of the root causes of DRM; and 3 – the identification of the required interventions to improve duty-bearers’ performance and build rights-holders’ capacities. Thus, according to the UN, a HRBA seeks “to deepen understanding of the relationships between rights-holders and duty-bearers, contributing to bridge the gaps between them” [27].

3. Health and human rights

The relationship between health and human rights is bidirectional. This means that health is a human rights issue, and conversely human rights are a health issue [29,30]. Both have been developed in the last seven decades under international law, mainly as a basis for public health. What is central to this relationship is that it offers a universal framework “to promote justice in public health, elaborating the necessary freedoms and rights to achieve dignity for all” [31].

Human rights are norms that aim to protect people from social and political abuse. They can be considered as moral, philosophical, judicial and political concepts which posit that “every human being possesses inalienable, universal rights, regardless of the statutory legal framework in force and independent of other factors such as ethnicity or nationality” [32]. Fundamental human rights are defined as a variety of an individual’s personal prerogatives, which democratic societies generally enshrine into law. Human rights are grounded in the political constitutions as a consequence of adhering to international conventions, and thereby ensure primacy is respected by governments and largely by all actors. It is noteworthy that in childbearing women and children, human rights address not only the actual person, fetus and child, but also the future adult.

The centrality of human rights concerning key health issues throughout the history of medicine can be found in historical public health policies, programs, and practices. There is well accepted evidence demonstrating that norms consecrated to the respect, protection, and fulfillment of human rights can translate into improved public health in several important health issues [33]. A prime example of previous use of HRBA in health issues is the campaign against the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS). In fact, policy makers were forced to ensure basic human rights protections in order to guarantee the access to care of HIV stigmatized and
marginalized populations [31,34]. By advocating for human rights, these population had improved access to health services and medications, as well as guaranteed availability of preventative measures and reduced discriminatory practices [35]. The HRBA in this context positively impacted HIV patients by reducing morbidity, mortality and disease transmission.

It is necessary to recognize that the existence, validity, and exact nature of human rights have been perennial topics of heated debates in regard to contentious rights or in controversial contexts. Nutritional care as a human right and the right to food, considering that without the latter life is unsustainable, can turn into such a disputed right in the context of clinical practice.

4. Nutritional care as a human right

4.1. The emergence of the right to nutritional care

Clinical nutrition has not yet been explored in the context of HRBA. Until now, it has been limited to promoting and claiming the right to food in the clinical context [36,37]. The Declaration of Cancun, signed in 2008 by FELANPE members, was based on the right to food and nutrition in hospitals [38]. Another example, the Resolution ResAP (2003) [22] on Food and Nutritional Care in Hospitals, adopted by the Committee of Ministers of the Council of Europe, was based on the right to food, as stated in the introduction: “access to a safe and healthy variety of food is a fundamental human right.”. By invoking the right to food and nutrition in hospitals, the right to be protected against hunger and the right to adequate food would be promoted. However, it is well known that although food is available in hospitals, it does not necessarily mean the patients will be able to ingest it as a consequence of their disease status. In this regard, acknowledging that the lack of food along with the disease will further deteriorate the patient’s nutritional status, and thus negatively impact on outcomes, nutrition care becomes a human right. Thus, we should ask: Why is the right to food neglected in the clinical field?

Surprising as it may seem, in hospitals (an essential institution for the care of persons seeking health improvement), this right is too often disregarded. Our hypothesis is that DRM does not fall within the scope of the concept or normative content of the right to food. Moreover, the right to food is within the scope of community malnutrition, a distinct form of malnutrition, the origin of which lies in food insecurity. Fig. 1 shows the different pathways of community malnutrition and disease-related malnutrition. It must be noted that according to the particularities of each form of malnutrition, a different approach is needed.

Therefore, we advocate that it is necessary to recognize nutritional care as a human right, taking into account the latter guarantees that all people should have access to food and evidence-based medical nutrition therapy including artificially administered nutrition and hydration (AANH). In this regard, the malnourished ill should mandatorily have access to nutritional care. In particular, screening, diagnosis, nutritional assessment and, with optimal and timely nutritional therapy in order to reduce the high rates of hospital malnutrition and the associated morbidity and mortality. This right does not imply that there is an obligation to feed all patients at any stage of life and at any cost. On the contrary, this right implies, from an ethical point of view, that the best decision for the patient must be made and this may include the decision not to feed, when terminality has been defined and the patients, families and/or caregiver together with the clinical team decide against it.

The Cartagena Declaration signed in 2019 for the first time proposes that nutritional care, understood as a holistic process of patient care, should be recognized as a human right [25,41].

4.2. The right to food in the clinical context

The Universal Declaration of Human Rights, adopted by the UN in December 1948, is the first document to recognize the right to food as a human right. It is therein considered as a constituent part of an overarching Right to Adequate Living Standards (Article 25): “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including (access to) food ...” [42]. The mandatory nature of this right (i.e. legally binding), was enshrined in the International Covenant on Economic, Social and Cultural Rights (ICESCR) in 1976. For the last four decades, international agreements have reasserted the right to food. For example, the Convention on the Elimination of All Forms of Discrimination against Women (1979) and the Convention on the Rights of the Child (1989). To date, 160 States have ratified the ICESCR and, thus, are legally bound to enact its provisions. Article 11 of the ICESCR establishes that “the States Parties to the present Covenant recognize the right of everyone to an adequate standard of living for himself and his family, including adequate food” and the Committee on Economic, Social and Cultural Rights (CESCR) general comment number 12 asserts the existence of every person’s right to be free from “hunger and malnutrition” [43,44]. Hence, this right encompasses two distinct ancillary rights: the first is the right to adequate food while the second is “the fundamental right to freedom from hunger and malnutrition”. Then, how should the right to food be understood within the clinical context?

In order to answer this question, it is necessary to address it at the political level. The beneficiary of the right to adequate food is an active individual to whom the State is obliged to provide an environment that permits them to “feed themselves”, but, failing this basic tenet, they, are to be provided with assisted feeding without compromising their dignity. Conversely, in the clinical context the right to adequate food should be conceived differently. In this context, the participation of a third person is a key element in understanding this right. This is explained by the fact that the act of feeding someone sick, who cannot reach his/her basic nutritional requirements, must be done by an expert, who can act within an interdisciplinary team of caregivers. This means that the patient has the right “to receive” nutritional therapy in the best possible manner that is to say, the right to “be fed” and to be treated and not the right to “feed themselves”. This also means that the right to health is linked to the right to nutritional care. Therefore, nutritional care must be considered an emerging human right. It is motivated by the need to move forward on key issues such as the promotion of better outcomes and cost-effectiveness. Clinical nutrition research and education as well as patient empowerment should also be integrated into fighting the disease burden along with malnutrition. To make progress in this matter, public policies and legislation on clinical nutrition are needed, and the promotion of the right to nutritional care is a way to achieve it. Furthermore, it is necessary to define nutritional care as a human right.

4.3. The definition of nutrition care as a fundamental right

The human right approach carries considerable rhetorical power and can help mobilize the force of public opinion in bringing about a change. It is thus essential to have clarity and precision about the real nature of human rights, and the role they can play. It is important to preserve their normative power and enable effective policy guidelines. In this regard, nutritional care as a human right must be well defined. According to different authors [45,46], an emergent human right can be defined in accordance to its foundation, its duty-bearers and its content or scope.

Dignity is the universally endorsed candidate for the core value of human rights [42]. It has been previously described as the link
between human dignity and nutrition [41,42]. In fact, the absence of nutritional care and AANH can constitute an offence against human dignity (Table 1).

Through nutritional therapy, it is possible to respect human dignity (i.e. a person’s right to be treated ethically and to be valued and respected for their own sake) [48]. This is achieved when individual autonomy, religious beliefs, and socio-cultural environments are considered cardinal to nutritional therapy [42]. While caring for the patients in need of nutrition care (i.e. malnourished patients), all these factors must be considered. Thus, respect for human dignity is the foundation of the right to nutritional care.

The second aspect concerning the definition of the right to nutritional care is the imposition of human rights on duty-bearers.
This means that human rights must be respected by all of the different stakeholders, not only the States, who are capable of fulfilling them. Beyond policy makers and other political stakeholders, scientists, and healthcare givers are also concerned with the right to nutritional care. The main issue at stake is the capacity of healthcare systems to provide optimal nutritional care.

Finally, the content or scope of human rights refers to the interests that define and ground them (e.g., health, autonomy and knowledge) and to the duties generated by these underlying interests. Thus, nutritional care is part of the holistic approach for the patient, and encompasses a process beginning with the identification of nutritional risk, assessment, and diagnosis, which aims to prevent and treat DRM by early provision of nutrition, ranging from normal food to evidence-based medical nutrition therapy (including AANH). The latter is considered as a medical intervention requiring a medical indication that aims to achieve a treatment goal, which in turn needs the informed consent of the patient. In summary, nutrition care encompasses the duty to feed ill patients by natural or artificial means in order to prevent DRM, contribute to better health and improve outcomes. Consequently, the content of a proposed nutritional care human right must be conceived in a close relationship to other human rights. From our perspective, it is possible to frame this duty in the scope of two well recognized rights: the right to food and the right to health. So, what does it mean to say that nutritional care is a human right?

States and duty-bearers, from a legal and political point of view, are bound by certain obligations. People can legitimately claim the effective implementation of these obligations. Consequently, duty-bearers are bound “to respect, to protect and to fulfill” the right to benefit from the entire process of nutritional care. The patient has the right to be screened for nutritional risk and diagnosed for malnutrition, and to receive a regular hospital diet or a therapeutic diet (i.e., food modification and supplements) or evidence-based medical nutrition therapy including AANH therapy under the care of an expert interdisciplinary team, and the government has the duty to guarantee said rights (Table 2). The question that arises is, how much nutritional care be related to the recognized human rights?

4.4. The right to health and nutritional care

Health is a fundamental human right that should be considered indispensable for the exercise of other human rights, in particular the right to food, and is, according to our proposed approach, the right to nutritional care [49].

The right to “the enjoyment of the highest attainable standard of physical and mental health” was first found in the 1946 Constitution of the World Health Organization (WHO). The preamble defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” [50]. The preamble further states that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.” Numerous international agreements protect this human right, for example, the 1948 Universal Declaration of Human Rights (Article 25), the ICESCR (Article 12), of the Convention on the Rights of the Child (Article 24), the Convention on the Elimination of All Forms of Racial Discrimination (Article 5), the Convention on the Elimination of All Forms of Discrimination Against Women (Articles 12 and 14), the American Declaration on Rights and Duties of Man (Article 11), and of the Convention on the Rights of Persons with Disabilities (Article 25) [51].

The right to health is closely related to and dependent upon the realization of other human rights, such as the right to food. The CESC general comment number 14 (Article 14) emphasizes that “The right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as food and nutrition ...” Thus, the right to health, the right to food and the right to nutritional care should be considered in a close relationship. Nutritional care is at the intersection of the right to food and the right to health. This approach and the indivisibility of these human rights can create opportunities for the implementation of rights-based legislation, policies, and programs for the realization of the right to nutritional care (Fig. 2).

5. The ethical approach

Human rights and health care ethics are closely linked as they support and complement each other when applied together [52]. Human rights norms are meant to guide the actions of governments, whereas ethics in health care much more broadly “encompass concern for the specific actions, inspirations, and relationships of individual health workers, researchers, and organizations” [52]. Human rights concepts, according to E. Hirsch, “characterize and illuminate the issues of an ethical requirement in the fields of care and research.” Thus, in the context of nutritional care, respect for human rights and dignity are not abstract values, but take on a practical dimension “which define a social order and place us in mutual obligations towards each other.” [53].

We believe that human rights and ethics provide unique and valuable guidance for the actions of parenteral and enteral (PEN) societies and other international organizations focused on clinical nutrition. The human rights norms and ethical values and principles can contribute to moving forward in fighting malnutrition in the clinical context. Recognizing the right to nutritional care as a human right establishes a commitment to a very important ethical responsibility that must be based on the respect of the four ethical principles (autonomy, beneficence, nonmaleficence, and justice) [54] as well as other principles such as vulnerability, equality, justice and equity [55,56].
In 2016, ESPEN published a guideline on ethical aspects of artificial nutrition and hydration focused on the adult patient that provided a critical summary for physicians and caregivers [57]. The four principles of the Bioethics are presented in the context of artificial nutrition and hydration covering different sceneries from the patient with dementia and their care in the intensive care unit to palliative care and the terminal patient.

The updated 2021 ASPEN position paper on ethics of AANH focuses on applying these ethical principles. Recommendations for preventing and resolving ethical dilemmas are addressed with an emphasis on a collaborative interdisciplinary approach following the twenty proposed ethics position statements. The laws of individual states and national governments have to be considered, but overall the international perspective on the ethics of AANH are essentially similar [58].

5.1. Developing a human rights-based approach to clinical nutrition: perspectives for clinical nutrition

Clinical Nutrition is a basic interdisciplinary and applied science, concerned with the caring of those in need of nutrition care (i.e. undernutrition, inadequate diet intake, overweight and obese patients). Its aim is to apply the principles of nutritional care in order to ensure a balance in nutritional status, and modulate other biological functions to positively influence the individual’s homeostasis, any healthcare treatment and outcomes [59]. We are convinced that recognizing that people have the right to nutritional care is a major advance in the field of clinical nutrition. The main importance of the HRBA approach is that it should help to identify major priorities and objectives in order to fight against malnutrition and to implement optimal nutritional care for all. In childbearing women and children, not only current health but also that of future generations is at stake. Among the priorities and objectives in the field of clinical nutrition, it is possible to identify the need to increase research and improve nutrition education for all health professionals [60], to emphasize the economic aspects thereof [61], to create an institutional culture that values nutritional care, and to promote patient empowerment as a necessary action to improve nutritional care [62]. Consequently, such priorities enable recognizing specific duties for the duty-bearers (policy-makers, institutional managers and caregivers) and the rights-holders (the patients). It is our aspiration to create interventions that improve the rights-holders’ capacities and the duty-bearers’ achievements, in order to bridge the gaps between them. From an ethical approach, recognizing nutritional care as a human right implies the ethical duty of feeding the ill person in conditions of dignity, while ensuring justice and equality.

Moreover, the realization of the right to nutritional care needs a multi-stakeholder approach. For example, the right to nutritional care could be at the core of the programs and the strategy of the ESPEN Optimal Nutrition Care for all campaign in Europe [63]. This initiative has been promoting and supporting the development of public health policy in clinical nutrition. Basing health policy on human rights can give the program additional strength. The patients’ associations or support groups should be mobilized and be aware of the recognition of the right to nutritional care.

Finally, the realization of the right to nutritional care must be a goal of state policies and programs regardless of their economic, social, cultural, religious or political background. To achieve this, the international working group recommends the following 10 principles:

1. Public health policy must make fulfillment of the right to nutritional care a fundamental axis in the fight against DRM;
Clinical nutrition must be integrated into public health policy based on human rights, equity and economic values;

2. Clinical nutrition education and research is a fundamental axis of the respect and the fulfillment of the right to nutritional care;
3. Ethical principles and values in clinical nutrition including justice and equity in nutritional care access is the basis for the right to nutritional care;
4. Clinicians, researchers and policy makers should work together to translate evidence-based medical nutrition therapy into policy;
5. To be effectively implemented, public health policy on clinical nutrition should consider all patients at nutritional risk, including childbearing women and children, as the target population;
6. Public health policy should consider nutritional care as part of the holistic approach for the patient, which aims to prevent and treat DRM and improve clinical outcomes;
7. Nutritional care requires an institutional culture that follows ethical principles and values, and an interdisciplinary approach;
8. All nutritional care must include an after-hospital discharge plan, involving patients and caregivers, and be subject to an annual audit;
9. Patient empowerment is a key enabler to necessary action to optimize nutritional care.

6. Conclusion

Our position is that nutritional care should be considered a fundamental human right intrinsically linked to the right to food as well as to the right to health. We propose that this analysis could contribute to the construction of a moral, political and legal perspective globally, in the concept of nutritional care. Moreover, it can be the cornerstone of the rationale of political and legal instruments in the field of clinical nutrition.

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Authorship statement

Diana Cardenas: Conceptualization, Analysis and Writing-Original draft preparation; Maria Isabel Toulson Davison Correia: Conceptualization, Analysis, Writing- Reviewing and Editing; Juan B. Ochoa: Analysis, Reviewing and Editing; Gil Hardy: Analysis, Writing- Reviewing and Editing; Dolores Rodriguez-Ventimilla: Writing- Reviewing; Charles Bermúdez: Writing- Reviewing; Karin Papapietro: Writing- Reviewing; Régis Hankard: Writing- Reviewing; André Briend: Writing- Reviewing; Katerina Zakka: Writing- Reviewing; Teresa Pounds: Writing- Reviewing; Winai Ungpinipong: Writing- Reviewing; Cristina Cuerda: Writing- Reviewing; Rocco Barazzoni: Conceptualization, Analysis, Writing- Reviewing and Editing.

Conflicts of interest

Diana Cardenas: none; Maria Isabel Toulson Davison Correia: Lecturer for Abbott, Baxter, Fresenius, Nestlé, Nutricia, Persan, Takeda; Rocco Barazzoni: none;

Katerina Zakka: none; Teresa Pounds: none; Winai Ungpinipong: none; Cristina Cuerda: Lecturer for Abbott, Baxter, Fresenius, Nestlé, Nutricia, Persan, Takeda; Rocco Barazzoni: none.

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