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Right to food for those in home enteral nutrition

Direito à alimentação adequada para usuários em nutrição enteral domiciliar

Abstract

Introduction: With the increase in the prevalence of chronic diseases and in life expectancy, the number of people who need to be fed by tubes, making use of enteral nutrition (EN), often at home (HEN), has increased. **Objective:** To analyze the effectiveness of the right to food (RTF) for those in HEN. **Methods:** Literature review and document analyses were carried out on the construction of public policies aimed at guaranteeing the RTF to citizens in HEN. Full articles published at any time in indexed journals were searched and after analyzing 154 publications, 15 articles were selected and organized into three categories according to the nature of their contributions: Lack of organization of the Health Care Network; Judicialization of the RTF; Successful experiences of state and municipal public policies. For the document analysis, official publications referring to federal and state public policies in this matter were sought. **Results:** This research showed that despite the Ministry of Health's initiative to support discussions on nutritional care protocols for citizens in HEN and successful experiences in some states and municipalities in Brazil, there is still no national policy that guarantees access to industrialized enteral formulas and nutritional assistance for those in HEN. **Conclusions:** Due to the lack of public policies guaranteeing the RTF for those in HEN, lawsuits continue to be one of the main means to achieve this right.

Keywords: Enteral Nutrition. Home Nursing. Food Security. Public Health Policy. Unified Health System

Resumo

Introdução: Com o aumento da prevalência de doenças crônicas e da expectativa de vida, tem crescido o número de pessoas que precisam se alimentar por sondas, fazendo uso da nutrição enteral (NE), muitas vezes em domicílio (NED). **Objetivo:** Analisar a efetivação do direito humano à alimentação adequada (DHAA) aos usuários do Sistema Único de Saúde em NED. **Métodos:** Realizou-se uma revisão da literatura e análise documental sobre a construção de políticas públicas neste campo. Foram buscados artigos completos publicados a qualquer período em periódicos indexados e, após a análise de 154 publicações, 15 artigos foram selecionados e organizados em três categorias quanto à natureza de suas contribuições: Falta de organização da Rede de Atenção à Saúde; Judicialização do acesso às fórmulas nutricionais; e Experiências exitosas de políticas públicas estaduais e municipais. Para a análise documental, buscou-se publicações oficiais referentes às políticas públicas federais e estaduais nesta matéria. **Resultados:** Esta pesquisa mostrou que, apesar da iniciativa do Ministério da Saúde em subsidiar as discussões sobre os protocolos de atenção nutricional para os usuários em NED e de experiências exitosas em alguns estados e municípios, ainda não há uma política nacional que garanta o acesso às fórmulas alimentares enterais e à assistência nutricional para esses usuários. **Conclusões:**

Devido à ausência de políticas públicas que garantam a realização do DHAA aos usuários em NED, as ações judiciais continuam sendo um dos principais meios para a realização deste direito.

Palavras-chave: Nutrição Enteral. Assistência Domiciliar. Direito à Alimentação. Políticas Públicas de Saúde. Sistema Único de Saúde.

INTRODUCTION

Although the Right to Adequate Food (RAF) has been stated as a fundamental right since 1948 by article 25¹ of the Universal Declaration of Human Rights, it was only in 2010 - through Constitutional Amendment No. 64 - that food was included as a social right in the Brazilian Constitution (Article 6).² Three years after the recognition of RAF in the Constitution, the updated version of the National Food and Nutrition Policy (PNAN) was published. It addresses crucial points such as promotion of healthy eating, comprehensive care for food and nutrition-related problems, RAF of individuals with special dietary needs related to the biological use of nutrients or feeding route (enteral or parenteral).³

As the population grows older, there is increased prevalence of non-communicable diseases (NCDs) that call for alternative feeding routes, e.g., enteral nutrition (EN).^{3,4} Performed through nasal tubes and ostomy procedures, EN is necessary when oral feeding is insufficient or unable to ensure RAF.⁵ When patients are clinically stable, EN can be performed at home (home enteral nutrition, or HEN), using commercial (processed) enteral formulas, food-based formulations (homemade) or mixed formulations (combining fresh foods, food products and commercial formulations).⁵ This scenario has required Brazil's Unified Health System (SUS) to organize health care provision to individuals with special dietary needs in home care. However, the commitment to ensure RAF to SUS users receiving home enteral nutrition is still not included in the public policy agenda.⁶

Ensuring access to adequate food for patients receiving HEN may require the use of commercial enteral formulas, which are expensive and lack specific funding from SUS, except in hospital settings.^{7,8} Faced with the lack of regulation and a line of funding for assistance to individuals with special dietary needs, some municipalities have organized municipal networks to implement nutritional care protocols for patients receiving HEN.⁸⁻¹⁰ However, there is wide variation in these guidelines and in the operations of these networks and protocols, which may ultimately impair the provision of nutritional care for individuals with special dietary needs.⁸⁻¹⁰

Furthermore, the lack of implementation of RAF for users receiving HEN has led to a significant increase in lawsuits against the three levels of SUS management, requesting the supply of commercial enteral nutritional formulas.¹¹ Although this phenomenon, known as "judicialization of health", is a legitimate way of demanding the realization of rights, it poses a problem for the Public Power. The main reasons are unplanned allocation of public resources, and overlapping of individual rights over collective rights, which increases inequities in access to health.¹¹ The need for funding and the design of protocols for provision of health care and prescription of nutritional formulas and, when necessary, their supply by the authorities, are recurring demands in decision-making environments and regional and national conferences attended by managers and counselors working in the social control of SUS.¹²

To overcome this organizational gap in the PNAN, a deeper analysis is needed of the behavior and institutional factors that lead to different forms of organization or even the lack of organization of health care services provided to individuals with special dietary needs at different levels of management in SUS. In political sciences, public policy analysis starts with the study of the problem; for Secchi,¹³ just as the diagnosis of the disease is imperative for the choice of treatment, before the design, amendment or elimination of a policy, a deep understanding of the public problem is required.

To analyze the public problem concerning the lack of effective implementation of RAF for SUS users receiving HEN, this study explored the history of design of public policies and organization of health care services aimed at ensuring RAF to patients receiving HEN in Brazil.

METHODS

The analysis of this public problem was guided by the steps proposed by Secchi:¹³ problem diagnosis, problem definition and goal setting. Problem diagnosis precedes the definition of problem per se and includes the analysis of context, amplitude, intensity and tendency. In the next step, the public problem is defined as a problem of scarcity (e.g., lack of jobs), a problem of excess (e.g., excessive use of pesticides) or a risk-related problem (e.g., risk of flooding).¹³ Finally, suggestions are made regarding what the objective of a public policy should be when tackling the problem being analyzed. Also, a problem tree is designed to help to identify the root (causes), the trunk (the problem itself) and the branches (consequences) of the problem.¹³

The problem was diagnosed by means of a literature review and document analysis of public policies aimed at ensuring RAF to patients receiving HEN in Brazil. The literature review was performed using the scientific databases VHL (Virtual Health Library), PubMed, SCOPUS (SciVerse Scopus), Web of Science and Google Scholar. Articles were searched by using the following strategy of combination of Descriptors in Health Sciences (DeCS): ("Judicialização da Saúde" OR "Serviços de Assistência Domiciliar" OR "Segurança Alimentar e Nutricional" OR "Política Nutricional") AND ("Nutrição Enteral") AND ("Sistema Único de Saúde"); ("Health's Judicialization" OR "Home Care Services" OR "Food and Nutrition Security" OR "Nutrition Policy") AND ("Enteral Nutrition") AND ("United Health System"). As an inclusion criterion, only complete articles published in indexed journals were previously selected (books, conference proceedings, theses, monographs and dissertations were excluded from selection), in any period (without restriction of publication date). After reading the abstracts of the previously selected articles, the researchers excluded those that did not address the object of study or that investigated the topic in international contexts.

Documentary analysis was made of official publications referring to federal and state public policies in this area (constitution, laws, decrees and ordinances, manuals, protocols, reports and handbooks published by the Ministry of Health and State Departments of Health). The searches were conducted on the websites of the Ministry of Health and State Health Departments, as well as on the electronic Official Gazette of the Brazilian States and the electronic Brazilian Government Gazette. Based on the data collected by the integrative review and document analysis, the public problem was defined and the problem tree was designed, providing the basis for setting the objective of the public policy that will tackle the afore-mentioned problem..

RESULTS AND DISCUSSION

Problem Diagnosis

A total of 154 publications were found in the scientific databases; 53 were selected for full reading; after analysis, 15 articles were chosen. The most frequent reasons for exclusion were publications that were not indexed (a total of 32), found in the Google Scholar database, and those in the format of book chapters, conference proceedings, monographs, theses and dissertations (a total of 63). The selected articles were organized into three categories as to the nature of their contributions to the diagnosis of the target public problem:

- I - Lack of organization of health care provision to SUS users receiving HEN.
- II - Judicialization of health for access to nutritional formulas by SUS users receiving HEN.
- III - Experiences with the implementation of public policies to ensure RAF to SUS users receiving HEN.

Table 1 shows the main results of Category I studies, that is, those that explored the impact of the lack of organization of health care on SUS users receiving HEN:

Table 1. 1st Category: results from the selected studies.

1st Category: Lack of organization of health care provided to individuals on home enteral nutrition (HEN).				
Title	Autos (Year)	Study design	Objective	Main results
Possibilities and limitations of enteral nutritional therapy based on the perspective of caregivers and professionals from a public health network in a border region.	Führ e Ciachi (2019) ¹⁴	Cross-sectional and qualitative-quantitative study.	To analyze the possibilities, limitations and challenges of HEN in the Public Health Care Network of Foz do Iguaçu-PR	<ul style="list-style-type: none"> • Among the 12 individuals on home enteral nutrition evaluated, the frequency of clinical complications, deaths and malnutrition was higher among those without nutritional home care. • Caregivers complained of disorientation and insecurity in the use of enteral nutrition at home. • There is a need for standardized guidelines and protocols to guide the nutritional home care for those on HEN.
Living of the caregivers in relation to domiciliary enteral nutritional therapy	Libório et al. (2016) ¹⁵	Field research with a qualitative approach.	To know the main doubts of the caregivers in relation to home enteral nutrition therapy in Dourados-MS.	<ul style="list-style-type: none"> • The main difficulty of caregivers was the acquisition of the commercial enteral diet. • Caregivers would like to know how to make adjustments in the enteral diet without compromising in quality.
Home Enteral Nutrition Therapy: interface between human right to adequate food and food security and nutrition	Mazur et al. (2014) ¹⁶	Theoretical study	To discuss the guarantee of the Human Right to Food for those on HEN.	<ul style="list-style-type: none"> • The use of commercial enteral diets for patients on HEN is subsidized in some municipalities and states in Brazil but there are no criteria for determining the need to use these diets. • Low-income families concerned about following the prescription received at hospital discharge attempt to purchase the commercial enteral diets, compromising their income to purchase food. • Criteria for home enteral nutrition must be established: individuals whose digestion and absorption of nutrients is not impaired should receive a prescription of homemade diet; individuals who are still in the acute phase or restoring their nutritional status should receive commercial diet.

HEN goes beyond the supply of enteral diets through tube feeding; it encompasses nutritional monitoring at home, prioritizing care for patients that require more attention. It also involves regularly monitoring nutrient intake, providing dietary advice, and providing support to patients and their caregivers,

so as to enable their active participation in each stage of diet therapy.¹⁶ The importance of implementing policies aimed at the organization of health care to ensure RAF to SUS users receiving HEN is evident in studies that show: reduced frequency of clinical complications among individuals receiving HEN who have nutritional follow-up at home; caregivers' difficulty in acquiring enteral formulations; and the impact of these diets on family budget, compromising the food and nutrition security of the entire family.¹⁴⁻¹⁶ When individuals who need HEN are discharged to continue treatment at home, they may feel left behind by SUS, since in many municipalities they are not guaranteed the receipt of commercial enteral formulas or nutritional monitoring with prescription of food-based formulas.

The increased prevalence of individuals receiving HEN around the world shows the potential magnitude of this public problem. In the United States, prevalence has increased from 463 individuals receiving HEN per million inhabitants in 1992 (597/1,000,000), to 1,385 individuals in HEN per million inhabitants in 2013 (1,382/1,000,000).¹⁷ In the UK, from 2009 to 2010, the number of individuals receiving HEN grew by 32%: from 5,190 to 6,851.¹⁸

As there are no records of the number of individuals receiving HEN in Brazil, one cannot calculate the incidence or prevalence of this phenomenon at the national level, but previous studies carried out in Brasília and Curitiba showed an increase in the prevalence of cases in these cities.^{19,20} In Curitiba, the prevalence of HEN increased by 425% from 2006 to 2015.¹⁹ At the same time, in Brasília, the prevalence of individuals receiving HEN increased from 5 per million inhabitants in 2000 (5/1,000,000) to 176 per million inhabitants in 2005 (176/1,000,000).²⁰

In the absence of structural or conjunctural factors of the social economic process that guarantee a certain social right, the Public Power can be prompted to enforce it.¹¹ Table 2 shows the main results of the Category II studies, which focused on the judicialization of health for access to nutritional formulas for SUS users receiving HEN.

Table 2. 2st Category: results from the selected studies.

2st Category: Judicialization of theright to food.				
Title	Autos (Year)	Study design	Objective	Main results
The access to nutritional formulas in the Brazilian National Health System: An overview by the justice system	Silva e Delduque (2019) ¹¹	Exploratory, descriptive, qualitative and quantitative study.	To analyze the perceptions of the justice system on the judicialization of the access to nutritional formulas.	Through interviews with 11 representatives of the justice system, it was observed: <ul style="list-style-type: none"> • The justice system does not understand the concept of food security. • There is a misunderstanding about the technical analysis of food formulas. • The lobby of the food industry is the most important factor that influences the judicialization of health. • Dialogue between the sectors is the most important strategy for confronting judicialization.

Table 2. 2st Category: results from the selected studies.

2st Category: Judicialization of theright to food.				
Title	Autos (Year)	Study design	Objective	Main results
Right to health and democratic participation: popular action in the processes of state health decision making	Mendes e Lima (2018) ²¹	Theoretical study	To reflect on food as a right to health in the judicialization of access to nutritional formulas.	<ul style="list-style-type: none"> • Enteral nutritional therapy symbolizes the right to health, as there is a relationship between good health and adequate nutrition. • The request for nutritional formulas through lawsuits has grown, becoming a problem for the government. • The need for funding and the implementation of protocols and guidelines are recurring demands among stakeholders. • Judicial decisions on health matters and access to nutritional formulas are based mainly on the prescription and its supposed urgency, without considering the safety and cost-effectiveness of using the requested products. • Judicial decisions for the provision of commercial enteral diet do not consider whether that treatment is the best in terms of cost-effectiveness, whether the individual really needs it or whether it could be replaced by another.
Profile of lawsuits over the access to food formulas forwarded to the brazilian ministry of health	Pereira et al. (2014) ²²	Exploratory and descriptive study.	To describe lawsuits over access to nutritional formulas against the Ministry of Health in Brazil in 2013.	<ul style="list-style-type: none"> • Between 2007 and 2013, there was a growing number of lawsuits over commercial enteral diet forwarded to the Ministry of Health. • This increase is due to the development of new technologies in health care, the pressure on the pharmaceutical industry on prescribers and users, greater understanding and enforceability of the population about their rights and greater access to the legal system. • Economic interests are involved, especially by those who produce new technologies in health care, including medications and nutritional formulas . • Decisions that are favorable to applicants, but made indiscriminately, compromise proper allocation of public resources and the organization of the Health System.

Como a saúde e a alimentação são direitos constitucionais, a solicitação de fórmulas nutricionais por meio de ações judiciais contra as três esferas de gestão do SUS tem apresentado um importante crescimento.^{11,2021} Por exemplo, considerando somente os processos encaminhados ao Ministério da Saúde para fornecimento de fórmulas nutricionais, de 39 processos registrados em 2007, houve um aumento para 168 em 2014, dos quais 41% foram solicitações de fórmulas enterais comerciais.²²

As health and food are constitutional rights, there has been a marked increase in the number of legal claims for nutritional formulas through lawsuits against the three levels of SUS management.^{11,20,21} For example, considering only the claims sent to the Ministry of Health for supply of nutritional formulas, there was an increase from 39 lawsuits filed in 2007 to 168 in 2014, and 41% of them were claims for commercial enteral formulas.²²

Unplanned allocation of public resources hampers the political-legal process of ensuring social rights from the perspective of distributive justice.^{11,22} In this sense, it is noteworthy that although there is no consensus on the application of the concept of distributive justice to health care, it refers to the choice of the best mechanisms for allocating (commonly scarce) public resources by the government, merit-based proportional equality, or individuals' needs.²³ Those who gain access to their rights through the courts are often the least socioeconomically vulnerable individuals who have the means and knowledge to do so.^{11,24} In this sense, the judicialization for the provision of enteral diets has fostered debate between SUS managers and representatives of social control, on the need to develop protocols that institutionalize nutritional care to ensure RAF to users receiving HEN as part of comprehensive health care provision by SUS.¹²

Given the lack of national or state protocols and a line of credit for acquisition of commercial enteral formulations, municipalities have implemented HEN protocols that provide for the nutritional monitoring of users and the use of handmade and mixed enteral formulas.^{8,9,24} Table 3 shows the main results of the Category III studies, i.e., those that reported experiences with the implementation of public policies to ensure the RAF to SUS users receiving HEN.

Table 3. 3rd Category: results from the selected studies.

3rd Category: Successful experiences of state and municipal public policies.				
Title	Author(Year)	Study design	Objective	Main results
Nutritional status and clinical evolution of the elderly in home enteral nutritional therapy: a retrospective cohort study	Menezes e Fortes (2019) ²³	Retrospective cohort observational study.	To evaluate the clinical and nutritional evolution of elderly patients on HEN.	<ul style="list-style-type: none"> • The Department of Health of the Federal District (SES-DF) has a program for the provision of special-purpose formulas - Home Enteral Nutrition Therapy Program (HENTP), regulated by Administrative Rule number 478, dated September 6, 2017. • The majority of patients on HEN presented maintenance or improvement of clinical and nutritional status. • Home enteral nutrition is important for the advancement of public policies, in addition to being a strategy for dehospitalization and humanization of health care.
Home enteral nutrition: clinical-nutritional analysis and outcomes of 10 years of public policy	Mazur et al. (2019) ¹⁹	Retrospective observational study.	To characterize the situation of patients on HEN, in the capital city in the south of Brazil.	<ul style="list-style-type: none"> • In Curitiba, Brazil, the Nutrition Assistance Program for People with Special Dietary Needs (PAN) began in 2006. • From 2006 to 2015, most of the 1,231 patients on HEN used homemade diet at home. • There was no association of homemade enteral diet with survival.
Strengthening the care of those with special dietary needs: an experience with blenderized diets, in Piraquara-PR	Sousa e Will (2017) ⁸	Experience report.	To share the experience of implementation of the Municipal Protocol of Special Diets, using handmade enteral diet, in the municipality of Piraquara, Paraná.	<ul style="list-style-type: none"> • Before the municipality had a Protocol that guaranteed the supply of commercial enteral diet in sufficient quantity to supply 50% of the nutritional needs of the patients, the rest having to be borne by the patient. • The Protocol established the nutritional monitoring of patients on HEN, the prescription of homemade diet and the provision of commercial diet for those in clinical situations that contraindicate the use of blenderized diets . • One year after the implementation of the Protocol, there was a 48% reduction in expenses, which made it possible to hire two more nutritionists to carry out the nutritional care of these patients.

Table 3. 3rd Category: results from the selected studies. (Continues)

3rd Category: Successful experiences of state and municipal public policies.				
Title	Authors (Year)	Study design	Objective	Main results
Access to enteral nutrition via SUS in Sao Paulo state	Dias et al. (2015) ²⁴	Descriptive study.	To describe how patients on HEN can request the provision of commercial enteral diet.	<ul style="list-style-type: none"> In 2012, the State of São Paulo published Resolution SS54 that establishes the Pharmacology Commission of the São Paulo State Department of Health and defines norms and procedures for requesting nutritional formulas. Patients on HEN who reside in the State of São Paulo and are assisted by public or private institutions may request the provision of commercial enteral diet by the State of São Paulo. The request can be made on a website and is analyzed by the Pharmacology Commission. Every four months, the request must be renewed in the case of long-term use.
Chemical evaluation of macronutrients and minerals from handmade enteral diets used in homecare nutritional therapy in the brazilian national health system	Jansen et al. (2014) ²⁵	Descriptive study.	To evaluate the nutritional content from homemade enteral diets prescribed in enteral homecare.	<ul style="list-style-type: none"> Home-made enteral diets prescribed by nutritionists showed good physical-chemical and nutritional quality after chemical analysis. The inclusion of diverse food, such as nuts and oilseeds, which can be easily transformed into powder and dissolved, improves overall nutritional quality and makes enteral diet more similar to the food their families eat.
Standardization of non-industrialized enteral feeding for home care: the experience of Campinas city	Borelli et al. (2014) ²⁶	Experience report.	To describe the process of standardizing homemade diets for use in home enteral nutrition in Campinas.	<ul style="list-style-type: none"> A group of nutritionists was set up to standardize the homeade enteral diet prescribed at hospital discharge and by the professionals working in Primary Health Care. Home-made enteral diets were analyzed in terms of physical-chemical and nutritional quality, ease of preparation and cost, and those that presented the best results were selected for the protocol. The protocol aimed to facilitate hospital discharge guidelines and nutritional home care, in addition to ensuring food security for patients on HEN.

Table 3. 3rd Category: results from the selected studies. (Continues)

3rd Category: Successful experiences of state and municipal public policies.				
Title	Author(Year)	Study design	Objective	Main results
Nutritional care program: historic landmark in public policy for people with special dietary needs in the City of Curitiba, Parana State, Brazil	Schieferdecker et al. (2014) ²³	Descriptive study.	To present the historical framework of the Nutritional Care Program for People with Special Dietary Needs (PAN), in Curitiba, Parana.	<ul style="list-style-type: none"> • In 2011, the Nutritional Care Program protocol was launched for people with special dietary needs. • Constructing the care protocol ensured the sustainability of the program, led to a greater engagement and satisfaction of the professionals involved and improved the quality of care of users.
Experience report: home enteral nutrition therapy - promoting the human right to adequate food for people with special dietary needs	Jansen et al. (2014) ⁹	Experience report.	To describe strategies to strengthen home enteral nutrition in Belo Horizonte, MG.	<ul style="list-style-type: none"> • A group of nutritionists from public hospitals and from the municipal health department was set up to discuss Home Enteral Nutrition. • This group presented the following results: construction of a protocol for the follow-up of patients in home enteral nutrition after hospital discharge; conducting an update course on home enteral nutrition for nutritionists in Primary Health Care; construction of a guide booklet for the patient's caregiver; analysis of the physical-chemical and nutritional quality of enteral diets used at home.
Standardization of non-industrialized enteral feeding for home care: the experience of Campinas city	Borelli et al. (2014) ²⁶	Experience report.	To describe the process of standardizing homemade diets for use in home enteral nutrition in Campinas.	<ul style="list-style-type: none"> • A group of nutritionists was set up to standardize the homeade enteral diet prescribed at hospital discharge and by the professionals working in Primary Health Care. • Home-made enteral diets were analyzed in terms of physical-chemical and nutritional quality, ease of preparation and cost, and those that presented the best results were selected for the protocol. • The protocol aimed to facilitate hospital discharge guidelines and nutritional home care, in addition to ensuring food security for patients on HEN.

Table 3. 3rd Category: results from the selected studies. (Continues)

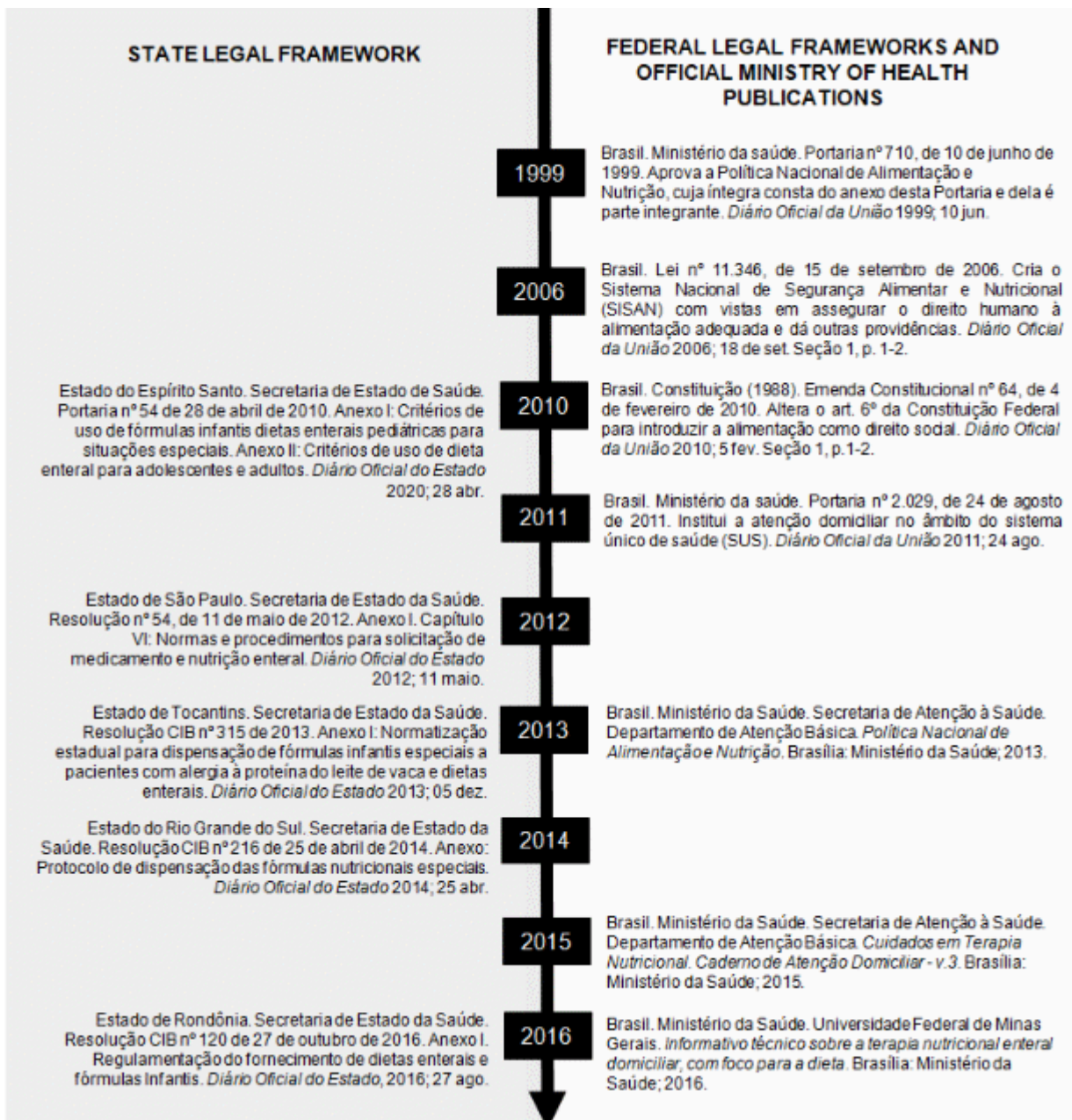
3rd Category: Successful experiences of state and municipal public policies.				
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Epidemiological profile and economic aspects of home enteral nutrition in the Federal District, center-west	Zaban e Novaes (2009) ²⁰	Retrospective cohort observational study.	To describe the evolution of home enteral nutrition in the Federal District, from 2000 to 2005.	<ul style="list-style-type: none"> • Costs of hospital enteral nutrition therapy were about 2.65 higher than the sametherapy at home. • After the publication of the first Technical Regulation for home enteral nutrition in the Federal District, in 2004, there was an increase in the number of patients. • There is a need for national legislations that may favor the development of home enteral nutrition.

Despite the successful experiences of some municipalities and states, in Brazil there are still no standardized health care criteria and guidelines for users with special dietary needs regarding alternative food routes.¹⁶ For example, there are municipalities that have established the supply of commercial enteral formulas in sufficient quantity to meet 50% of the nutritional needs of patients, while the remainder has to be paid for by patients themselves.⁸ Others prescribe handmade and mixed enteral formulas for patients with a stable health status, and supply commercial enteral formulas to the ones in more serious clinical situations (malabsorptive syndrome, pressure injury, etc.).^{8,16} When handmade and mixed enteral formulas are prescribed, the problem lies in the fact that these formulations lack standardized quality, with studies demonstrating that many of them have low nutritional quality.^{28,29}

In municipalities where there is no supply of commercial enteral formulations, or HEN protocols using homemade and mixed enteral formulas, families make an effort to purchase these products regardless of their cost, which often compromises household income, affecting the purchase of food and, therefore, the food security of families.¹⁶

Document analysis resulted in legal milestones for the implementation of policies to provide commercial enteral diets to users receiving HEN, technical publications of the Ministry of Health, and national policies that provide for the guarantee of the right to food for individuals with special dietary needs in home care. Figure 1 shows the results of document analysis in chronological order of publications.

Figure 1. Legal marks of policies aimed at guaranteeing the Right to Food to individuals on home enteral nutrition.



In the last two decades, the recognition of food as a fundamental social right for human beings has gained evidence and supported the implementation of public policies focused on ensuring RAF.³⁰⁻³⁸ Legal frameworks of this process include the publication of the PNAN³⁰ in 1999 and its update in 2013,³ the enactment of the Organic Law on Food and Nutrition Security (LOSAN) in 2006³¹ and the recognition of RAF in the Brazilian constitution in 2010.² The implementation of home care by SUS in 2011 was a milestone for the National Policy for Home Care (PNAD), which involves actions for health promotion, disease prevention, treatment, rehabilitation and palliative care in households, in association with Health Care Networks.^{32,33} Thus, ensuring RAF to patients receiving HEN is a condition for compliance with the Organic Law on Food and Nutrition Security and for the implementation of the National Food and Nutrition Policy within the scope of the National Policy for Home Care.

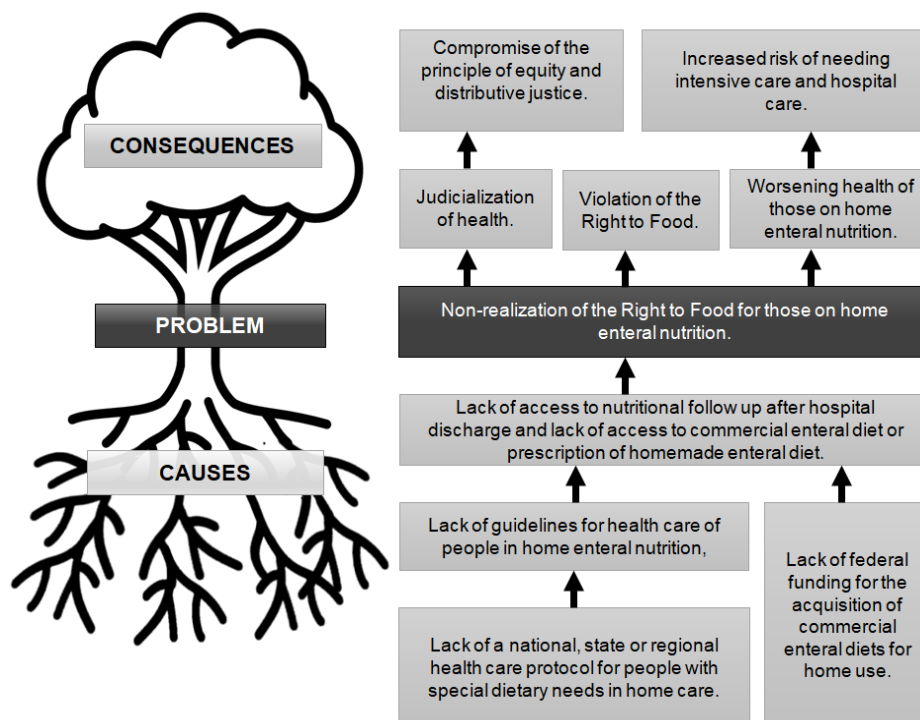
Problem Definition

The analysis of the studies showed a non-standardized organization of health care services for individuals with special dietary needs in home care, owing to the lack of a national, state or regional protocol. This has resulted in the widespread use of judicialization as an instrument to ensure RAF to SUS users receiving HEN. Therefore, it is a public problem of scarcity, caused by the lack of political-institutional mechanisms that can support the structure of health care services for SUS users receiving HEN that wish to exercise their RAF.

Goal Setting

The problem tree (Figure 2) shows the main causes of the lack of effective implementation of RAF for users receiving HEN, and the resulting effects of this problem. The deeper the objective of a public policy, that is, the more focused on the root of the problem it is, the more effective and complex it will be.¹³ In this way, it is evident that the establishment of a national, state or regional protocol for standardized assistance to patients receiving HEN, with provision of nutritional monitoring, is a premise to implement their right to adequate food, guarantee the protection of their health and avoid judicialization. Considering the lack of federal funding for the purchase of enteral formulas for home use, municipal protocols^{8,16} that provide for the prescription of handmade formulas or mixtures for clinically stable patients, and the provision of commercial formulas for those with certain clinical conditions, are good strategies to ensure equitable access to HEN. The concept of equity adopted in SUS can be summarized as providing health care services to individuals according to their needs, offering more to those who need it most, and less to those who require less care, which is similar to the above-mentioned concept of distributive justice.²³

Figure 2. Problem tree: non-realization of the Right to Food for individuals on home enteral nutrition.



CONCLUSIONS

Although many studies have demonstrated the importance of HEN to maintain and recover patients' health when oral feeding is unfeasible or insufficient, little is said about the difficulty of access to enteral formulas for those who have them as the only form of feeding. Despite the Ministry of Health's initiative to support debate on nutritional care protocols for SUS users receiving HEN, through the publication of technical manuals, and successful experiences in some states and municipalities in Brazil, little progress has been made in terms of implementing nutritional care for individuals with special dietary needs receiving HEN as part of comprehensive care services offered by SUS.

Because of the lack of social effectiveness of public policies to ensure RAF to SUS users receiving HEN, lawsuits continue to be one of the main means for the realization of this right. There is an urgent need to implement policies aimed at ensuring RAF to this population, guided by the principle of equity and distributive justice.

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