DOI: http://dx.doi.org/10.12957/demetra.2014.10520

Nutritional care program: historic landmark in public policy for people with special dietary needs in the City of Curitiba, Parana State, Brazil

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Abstract

This paper aims to draw the historical framework of the Nutritional Care Program for People with Special Dietary Needs (PAN), the advancements and challenges in public policy for people with special dietary needs in the city of Curitiba, Parana state, Brazil. Historically, PAN was created to replace the former Enteral Diets and Special Milks Program and to organize nutritional care in the city, so as to offer better nutritional care to these people, based on the principles of the Unified Health System (SUS). In this perspective, we attempted to draw the historical framework of PAN in the management of public policies within the SUS, and at such a landmark, the impact in management, professionals and users involved in this process.

Key words: Nutrition Therapy. Public Policy. Health Public Policy. Disabled People. Human Rights. Unified Health System.

Introduction

Food and nutrition are determinants of health and the human life. At the individual and collective levels, such attributes are underlined in the Universal Declaration of Human Rights proclaimed 50 years ago, ratified in the International Covenant on Economic, Social and Cultural Rights (1966) and incorporated to the country's legislation in 1992.[1-3]

The Human Right to Adequate Food (HRAF) is everyone's inherent right to have regular, permanent and unrestrictive access, either directly or by means of financial aids, to safe and healthy foods, in adequate and sufficient amount and quality, consistent with the people's cultural traditions, and ensuring a free-of-fear, worthy and thorough life in its physical, mental, individual and collective dimensions.[4]

Nutritional therapy (NT), which is based on the assurance of HRAF, aims to provide the appropriate nutrients required by the body and also to maintain or regain good nutritional condition, reduce risks of complications, promote quick recovery, reduce the hospitalization time, morbidity and mortality. Home nutritional therapy (HNT) is a kind of nutritional care provided at home, which seeks to improve the individual's quality of life with an improved prognosis of his clinical condition associated with social and family life.[5,6]

Individuals with special dietary needs in terms of alternative feeding should also have their HRAF assured by public policies. Based on the implementation of these policies, the nutritional care will be conceived as part of the whole care provided under the Health Care Network (HCN), being the primary healthcare the coordinator and supervisor of the network.[7]

Based on the above, this study aims to draw the timeline of the Nutritional Care Program (or PAN) for People with Special Dietary Needs in Curitiba, Paraná, describing its historic milestones, i.e., the progress and challenges with respect to the public policies for persons with special dietary needs.

Method

A survey of the historic data was conducted, beginning in 2002 with the implementation of the healthcare service for people with special dietary needs. Data were obtained from electronic spreadsheets on PAN's users and official documents of the Municipal Secretary of Health (MSH) of the City Administration of Curitiba.

Results

History of the Nutritional Care Program (2002 to 2006)

The legislation in effect on NT is the Resolution of the Collegiate Board no. 63, which sets down the Technical Regulation for NT in hospitals and services covered by SUS (the Brazilian Unified or Public Healthcare Service), and the Ordinance of the Ministry of Health no. 120, which also regulates NT.[5,8]

From 2002 on, the Secretary of Health of Curitiba began to monitor the demand of requests for industrial food formulas (IFF) such as supplements, complete formulas and infant formulas for special situations. During this period, requests for IFFs were accepted according to the prescriptions issued by hospitals and outpatient specialized services, and the formulas were purchased directly by an administrative clerk without any product standardization.

However, due to the increasing demand for outpatients requiring the continuity of NT after discharge, from 2004 there has been a need to organize this service, and a nutritionist at the central administration level was designated to assess the cases and a more effective dispensing. At that time, monitoring of the nutritional status, together with data on weight and height of the beneficiary patients, was performed by the primary care team of the healthcare units (PHU), who periodically sent the data to the nutritionist at the central level. Since then, some minimum criteria for the provision of IFF were defined, with standardized technical and nutritional specifications of the products; definition of nutritional diagnoses; and epidemiological analysis of the data, which culminated in the preparation of the first version of a protocol, firstly denominated Program of Enteral Diets and Special Milks in the Municipality of Curitiba.

Even with such provisions, some difficulties resulting from the lack of practitioners specialized in NT and food allergies and intolerances were observed. The main difficulties encountered by the nutritionist at the central level were: distribution of products without proper assessment and specific monitoring according to the patients' progress; difficulties in the assessment of bedridden patients; lack of instructions for the proper use of the products provided to the patients such as preparation, hygiene, storage and administration; great variety of product requests in terms of brands and flavors; lack of dietary guidance adjunct to the products use; uncertainty of the healthcare team in assessing the suspension of the product; and, finally, the sustainability of dispensing the products provided by the city administration.

From 2004 to 2005, an agreement was made with higher education institutions (HEI) in the city for the implementation of a pilot project, in which Nutrition undergraduates would perform the nutritional evaluation of HNT individuals, aiming at laying the grounds and supporting the necessary organization of the healthcare service provided to these outpatients. Such agreement enabled the diagnosis of the situation of HNT users in the municipality and contributed to enhance the training of the HEI students because of direct contact with the population.

Beginning in 2006, the MSH drafted a proposal for implementation of a new program for nutritional care in its broadest sense, i.e., a full, comprehensive care, not limited to the distribution of food formulas. Such proposal conforms to the fundamentals and guidelines of the National Policy for Primary Health Care, such as universal access, comprehensiveness and longitudinality of the care.[7] To put this new concept into practice, the MSH added to its staff ten nutritionists in primary care, one for each Sanitation District and one at the central level to coordinate the actions related to this subject, which enabled an individual care of persons with special dietary needs.

It is considered special dietary needs when an individual cannot eat normally because of some disorder or associated disease, requiring a specific nutritional planning. Such condition include children with food allergies or intolerances, patients with secondary malnutrition due to a disease and those with a disease that prevents the normal functioning of the digestive system resulting in poor absorption and/or the use of enteral feeding tube. With the new professionals supporting the primary care team it was possible to reorganize the Program of Enteral Diets and Special Milks, which passed to be called PAN.

PAN History - 2006 to 2011

With the arrival of the nutritionists, joint efforts were made in order to have a diagnosis of the situation of the individuals under the MSH care, consisting of nutritional assessment and the use of the products provided. At the time, new problems were encountered, relating to: evolution of the feeding route; continuity of enteral diet to provide 100% of food via tube; refusal to use the products provided, with remaining stocks existing at the patients' home; improper use of the amount of products prescribed; and food intake not compatible with a condition of food allergy – i.e., some products have been provided without being needed.

In order to enhance the knowledge of the nutritionists working at PAN, the MSH contracted the services of a firm specialized in courses, textbooks and instructional materials in the area of Nutrition, to train and qualify the nutritionists on HNT and to develop of a handbook for

nutritional care. During the course, the handbook previously prepared by the firm received contributions from the MSH nutritionists in order to adapt it to the reality of the primary care, and then it was called *Manual de Cuidados Nutricionais de Curitiba* (Handbook for Nutritional Care in Curitiba). The constructed material was the basis for the training conducted and would serve as support material for PAN, because it contained technical guidance for HNT management such as access feeding routes, food formula categories and methods of nutritional assessment.

Based on this handbook, the Protocol for Nutritional Care in Curitiba was constructed. As part of the professional development, an agreement was made with the Department of Nutrition of the Federal University of Paraná and the Center for the Collaboration on Food and Nutrition in the Southern Region (CECAN-Sul) for continuing education on the most varied themes, such as kidney failure, cancer, neurological disorders, dysphagia, allergy to cow's milk protein, diabetes, and lectures on dietary techniques in nutrition laboratory for the preparation of non-industrial foods.

Non-industrial formulas are mainly used for clinically stable users, with chronic diseases or in palliative treatment, not necessarily in terminal patients, requiring HNT. In Brazil, both types of formula, commercial and with foods, are used at home; each one has its specificity, according to the clinical diagnosis, prognosis, nutritional profile and also the family' socioeconomic condition. For the nutritionists work, equipment such as portable scales, plicometers, stadiometers and tapes were acquired with funds provided by the MSH of Curitiba and the federal government.

In addition to the qualifications, training for the users' care and nutritional evaluation, the nutritionists' staff of MSH interacted providing practical knowledge, thus contributing to the systematization of the PAN service through the standardization of workflows, norms, and procedures. In this period, contacts with specialized ambulatory and hospital care services in the city were arranged with the purpose of integrating the practices of care that the individuals received in different aspects of healthcare.

With the increased number of cases of children with allergy to cow's milk protein (ACMP), the MSH recognized the importance of having in its staff a specialist in this kind of care. So, in July 2007, a pediatrician specialized in gastroenterology joined the team to work specifically on the PAN's cases of ACMP and lactose intolerance. In 2009, with the implementation of the Center for the Support of the Family's Health (CSFH) in the city, the staff of nutritionists expanded to 29 professionals. Later, in October 2013, one more allergy specialist joined the team to meet all program demands.

Implementation of the Protocol: a historic achievement

Between 2006 and 2011, the efforts for the systematization and organization of the care service were continuously refined until April 2011, when the Protocol was officially launched and published, being validated by various scientific organizations.[9]

Among the PAN outcomes, it can be cited the multi-skilled integrated care which has had a key role in the clinical and emotional support to the patient and family; the humanization of treatment by caring the patients at home, providing more comfort and safety to the patient and family; periodical healthcare actions that provide increased safety in the treatment through monitoring and interventions when needed; individualized assessment according to the patient's needs; customized dietary planning, according to the family's habits and culture; serving a larger number of users and support to the inter-sectorial work of various secretaries and bodies of the city administration.

In addition to the Protocol, other support materials were developed by the MSH to assist in the development of PAN-related activities, such as the *Cartilha de Terapia Nutricional Enteral Domiciliar – TNED* (Guidelines for Home Enteral Nutritional Therapy), the *Cartilha de Alimentação Infantil*[10] (Guidelines for Children Nutrition) and also the *Cartilha* de *Alimentação para uma Vida Saudável* (Dietary Guidelines for a Healthy Life) available at the website of MSH of Curitiba.[11]

The implementation of PAN attains the goal of the National Policy of Food and Nutrition (PNAN),[1] which emphasizes the need for a better organization of the healthcare services in the country with respect to the main demands arising from disorders related to poor nutrition, such as malnutrition, obesity, specific nutritional needs, and non-communicable chronic diseases. It also includes in the list of demands for SUS nutritional services the care of individuals with special dietary needs (PNAN, 2012).

Figure 1 shows the timeline of the actions taken towards the care of people with special dietary needs in the MSH of Curitiba.

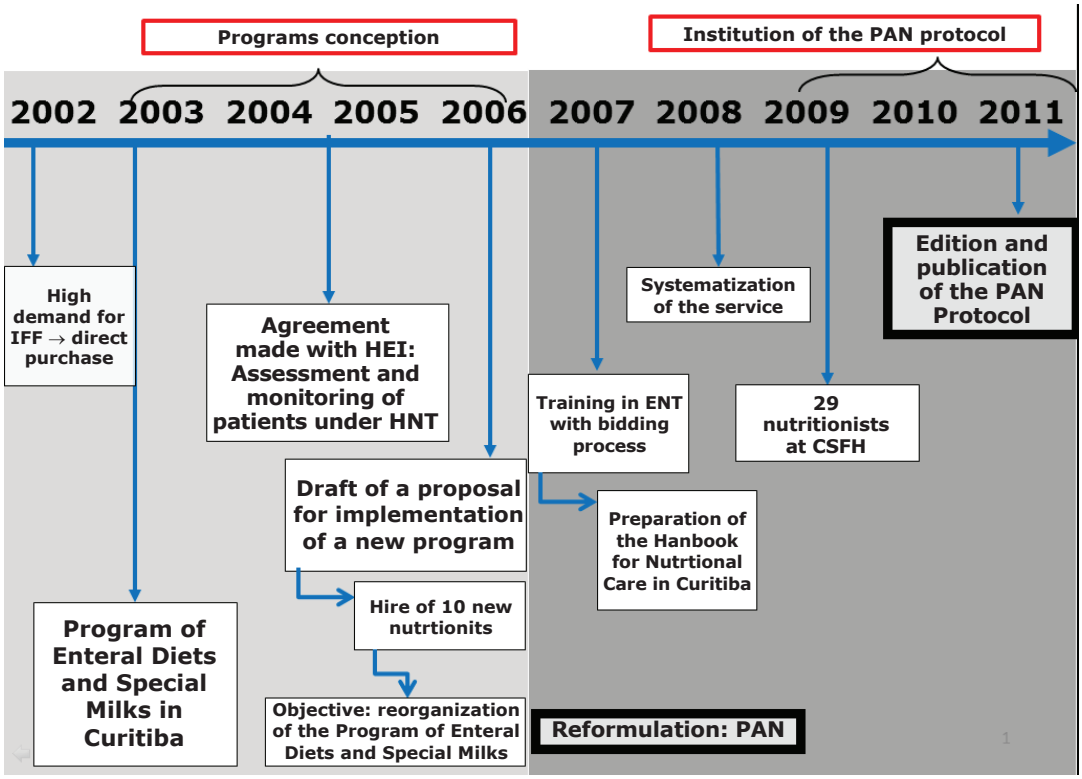

Figure 1. Implementation timeline of the Program of Nutritional Care. Curitiba-PR, 2002 to 2011.

Notes: IFF: industrial food formulas; HEI: Higher Education Institutions; HNT: Home Nutritional Therapy; ENT: Enteral Nutritional Therapy; CSFH: Center of Support to Family Health; PAN: Program of Nutritional Care of People with Special Dietary Needs.

Yesterday, today and tomorrow: advances and prospects for PAN

Since the implementation of PAN in 2006 until December 2013, a total of 5,173 patients received treatment. The number of patients rose from 647 in 2006 to 1,529 in 2013. The service, as already mentioned, aims primarily to nutritional care, which goes beyond simply distributing IFFs.

According to data analysis of patients included in PAN in December 2013, of 785 patients who continued in the program, 35.3% received nutritional guidance and monitoring by the PHU staff, without provision of IFF. PAN care services include: children (50.3%), elderly persons (25.5%), adults (14.8%) and adolescents (9.4%). Of the patients served, 57.7% go to the PHU and 42.3% remain at home because of mobility difficulties, although all patients receive at least one home visit of the nutritionist to know the family's conditions and way of life.

With respect to the groups of common diseases of people served by PAN, the leading one is ACMP (30.3%), followed by diseases of the central nervous system, particularly cerebral palsy and dementia (24%), cancer (11.2%), circulatory disorders, especially cerebrovascular accident (9.9%), kidney diseases, mainly chronic (2.2.%), and other diagnoses (22.4%).

The feeding route of the people served by PAN is oral (56.3%), followed by feeding tubes (37.7%) and mixed, i.e., oral associated with tube (6%). Of 37.7% of the patients being fed by enteral tube, what predominates is gastrostomy (69.9%).

Considering the growing demands for the care of people with special dietary needs in the public primary care, there is a need for development and improvements in PAN's actions and operations to make them suitable and appropriate for users, according to their needs, and also in some sectorial and inter-sectorial aspects. So a closer approach to ambulatory and specialized health care is crucial, in order to strengthen the efforts in the network and a better attention to the health of these individuals. Given the above, a regular and systematic review of the program protocol is essential. Continuing education is another aspect to be pursued so as to ensure a continuous training and update of the professionals who serve HNT patients.

The organization of PAN consists of a key milestone for SUS, and it is hoped that the work presented here might foster further studies, once references on HNT protocols in primary health care are very scarce.

Final considerations

PAN's historic framework showed that there was progress in the quality of care of patients with special dietary needs. Constructing the care protocol ensured the sustainability of the program, led to a greater engagement and satisfaction/security of the professionals involved and, especially, attained the goal of the proposal to improve significantly the quality of care of users.

Acknowledgements

The authors wish to thank Danielle Rodrigues Lecheta, nutritionist responsible for the systematization of the PAN protocol in the Municipal Secretary of Health in Curitiba and, on behalf of nutritionist Cristiane Aparecida Azevedo de Assis Machado, would like to thank all other nutritionists for their support in the construction of the PAN protocol, and to all those who use it in the Health Care Units in the MSH of Curitiba.

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Received: April 15, 2014
Revised: May 29, 2014
Approved: July 07, 2014