

# Experience report: home enteral nutrition therapy – promoting the human right to adequate food for people with special dietary needs

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## Abstract

This is an experience report of a project developed by the Working Group on Home Care Enteral Nutrition Therapy of Belo Horizonte, Minas Gerais state. The partners of this project are ten public hospitals and the Municipal Health Department of Belo Horizonte. The aim was to qualify the nutritional home care offered by the Health Unified System (SUS). To date, the results were a routine of hospital discharge of individuals under enteral nutrition, refresher courses on home care enteral therapy to nutritionists from the Family Health Support Center, a handbook for caregivers of patients under home enteral therapy and chemical analysis of macronutrients and minerals from homemade enteral diets prescribed after hospital discharge. The next steps will be the chemical analysis of vitamins of the homemade diet, the design of a technical handbook on home enteral nutrition therapy for primary care professionals and the creation of digital learning material for distance education. Outcomes of the project include an assisted referral of hospital discharge patients to primary care and better trained and qualified staff in the management and care of home enteral nutrition therapy. Soon, the project will provide low cost and easy-to-prepare homemade enteral formulas with known chemical composition, benefiting thousands of individuals and promoting the human right to adequate food for people with special dietary needs.

**Key words:** Food Security and Nutrition. Nutritional Therapy. Enteral Nutrition. Home Care. Health System. Adults.

## Contextualization of the experience

The wider top of the age pyramid, with the increase in the relative share of the population aged 65 or older from 5.9% in 2000 to 7.4% in 2010, associated with longer life expectancy,<sup>1</sup> impacts health processes, with higher prevalence of age-related diseases such as chronic, non-communicable diseases (NCDs) and neurodegenerative diseases. This phenomenon has led to a reorganization of the health system in Brazil.<sup>2</sup>

The Action Plan to Combat DCNTs by the Health Ministry<sup>2</sup> emphasizes, among other targets, comprehensive care and health promotion, whose main activities include the training of teams of primary care with investments in telemedicine and expansion of home care to people who need regular or intensive care but not hospitalization, such as clinically stable frail elderly, and bedridden individuals.

In this context, care during home enteral nutrition therapy is increasingly common, especially in patients with oral diseases that result in bankruptcy, such as head, neck or esophagus cancer and neurological diseases and disorders.<sup>3,4,5</sup> Often, in these clinical situations, enteral nutrition therapy (ENT) and use of nutritional formulas are needed for prolonged periods, in order to preserve or restore the nutritional status.<sup>3</sup>

The TNE at home is a viable and advantageous alternative because it promotes the interaction of individuals with families, improving comfort and quality of life.<sup>5,6</sup> Moreover, it contributes to ensuring the right to adequate and healthy for those with special dietary needs power, following the guidelines and objectives of the National Food and Nutrition Policy (NFNP)<sup>7</sup> the National System for Food and Nutrition Safety (NSFNS).<sup>8</sup>

NFNP defines the priority preventive actions and treatment of obesity, malnutrition, specific nutritional deficiencies and chronic non communicable diseases related to diet and nutrition. But it also points out that there is a demand for nutritional care in the Unified Health System (SUS) for individuals with special dietary needs.<sup>7</sup>

It is known that there are numerous diseases and health problems that, throughout the different phases of life, which can cause changes in the dietary needs of each individual. Special dietary requirements are defined in NFNP as:

*Dietary needs, whether restrictive or additional, in individuals with metabolic or physiological changes that cause temporary or permanent changes in the biological use of nutrients or via food consumption (enteral or parenteral).*<sup>7</sup>

In this sense, people with special dietary needs are considered vulnerable individuals to food and nutrition unsafety, and they require policies to promote the Human Right to Adequate Food.<sup>8</sup>

Home ENT is a known therapy, present in the U.S. for over 25 years. In Brazil, studies from the Group of Enteral and Parenteral Nutrition Support between 1990 and 1999, showed that there was an increase of 64% in prescriptions of ENT.<sup>9</sup> Data from the British Society for Parenteral and Enteral Nutrition show that at the end of 2007, there were 21,858 people under home ENT, representing an increase of 11.6% in a year.<sup>10</sup>

The transfer of patients from hospital to home requires proper family structure, training and caregiver assistance because caregivers must assume responsibility for all tasks related to the preparation and administration of diet and care of the patient and the tube.<sup>11,12,13</sup> Many family members of individuals under ENT report the transfer to the household as positive, because it is an opportunity for the patient to be near his or her family.<sup>5</sup> However, show vulnerability, fear of the future, anxiety, insecurity, isolation in the new function and inability to pleasure and happiness with the patient as ambivalent feelings.<sup>12,13,14</sup> Thus, this family needs the assistance of trained and skilled in handling this type of home care teams, considering the high complexity of the care of these individuals.<sup>5, 6, 11,12,13</sup>

In the discussion of the subject of care offered to individuals in the home center TNE is diet. According to the National Health Surveillance Agency (ANVISA) and according to RDC Resolution No. 63, of July 6, 2000, enteral nutrition in the diet is every food, for special purposes, formulated and developed for use in catheters or orally; it can be commercially produced or not, being used in hospital system, outpatient environment, or at home.<sup>15</sup>

There are several commercial formulations on the market and the advantage of most of these are the nutritional composition, osmolality and adequate stability, in addition to microbiological safety.<sup>16</sup> In hospitals, they are used and funded by SUS only in hospitals authorized according to Directive SAS/MS No. 120 of 14 April 2009.<sup>17</sup> So when home ENT is prescribed for a long period, guidance is given o the use of homemade formulas, or partially homemade formulas, which are not always nutritionally adequate.<sup>16,18</sup> Many of these formulas are composed of fresh food available in the household, diluted, liquefied and sieved without standardization of household measures, procedures for the preparation and cooking time, compromising the nutritional composition.<sup>19</sup> The lack of standardization can increase the risk of malnutrition and comorbidities, such as pneumonia, anemia, respiratory and urinary tract,<sup>20,21</sup> as well as contributing to hospital readmission<sup>9</sup>.

In the literature, there are few studies that suggest nutritionally complete handmade enteral diets, with low cost, stability and appropriate osmolality. There are some appropriate proposals in macronutrients, but with few studies regarding micronutrients.<sup>22,23</sup> Most studies of the chemical composition of homemade enteral diets use chemical composition tables, without taking into account the losses that occur due to food processing.<sup>24</sup> There are not enough bromatological and experimental studies that accurately quantify the macro and micronutrients, ensuring appropriate throughout treatment nutritional support, preventing the emergence of nutritional deficiencies.

Another problem of homemade enteral diets relates to their microbiological safety, the need to control the hygienic conditions of preparation, packaging and administration.<sup>15</sup> A recent study found 24% of samples of handmade enteral diets contaminated with mesophilic bacteria and 36% with faecal coliforms,<sup>22</sup> thus warning nutritionists of health teams to the need to correct weaknesses in the manipulation by caregivers, as well as guide and monitor the preparation of diets in households.

The various diet-related factors, from prescription to preparation at home, point to the need for the introduction and qualification of this theme in undergraduate courses in Nutrition, as well as investment in the process of continuing education for dietitians who work in health services.

The cost, an argument often used in defense of handmade diets, do not always justify their prescription, because some homemade formulations available in the literature show similar cost to that of commercial diets.<sup>16</sup>

It is understood, therefore, that dietary techniques and experimental study of the food matrix are required to analyze and determine the composition of handmade diets and confirm their applications in home ENT, coupled with a proposal to make them low cost and easy-to-prepare, and to reduce errors from household measures and the risk of contamination in the preparation, storage and administration of the diet process.

Thus, in order to qualify the nutritional care offered within the home care by SUS in the city of Belo Horizonte-MG, the project "Home Enteral Nutritional Therapy project: - promotion of the human right to adequate food for people with dietary special needs" was developed with a view to contribute to ensuring the human right to adequate food groups to patients with special dietary needs.

## Method

This paper is a report of the experience of the Home Nutritional Therapy Working Group of Belo Horizonte, Minas Gerais.

In public hospitals of this city, discharge of patients with alternative feeding has always been a problem for teams of hospital nutritional support and, in particular, for nutritionists. The main drawbacks were the high cost of commercial enteral diets, the reduced quality of many homemade diets, the low purchasing power of most SUS users and the short time available after hospital discharge to teach the patient's family how to prepare and administer the diet at home. Additionally, Family Health Teams (FHT), Family Health Support Centers (FHSC) and the Home Health Care Program (HCP) had difficulty providing care to these individuals, and there were no reference and counter-reference flows between levels of health care. These factors hindered the resolution of problems arising from this type of feeding, resulting in malnutrition and debilitation of the patient, worse quality of life and frequent rehospitalization.

Thus, in mid-2009, the Home Nutritional Therapy Working Group was set up. Members are professors of the Undergraduate Nutrition Program, Federal University of Minas Gerais (UFMG), and nutritionists from FHSC and from three public hospitals in Belo Horizonte. The first activities of the group were the development of a hospital discharge flow of patients under enteral nutrition, a refresher course in home ENT for nutritionists from FHSC, and the development of a handbook for patients' caregivers. However, these activities did not reach most patients and caregivers, because few public hospitals had joined the initiatives, which hindered the accomplishment of the group's objectives.

In order to solve this problem, a proposal was made to the Minas Gerais Research Support Foundation (FAPEMIG) to expand the project, according to Notice 07/2012, and awareness-raising work was done with other public hospitals in Belo Horizonte, which became partners in this project. The strategy used in this awareness-raising initiative was the possibility of chemical analysis of homemade enteral diets prescribed at discharge and the implementation of the discharge flow, as a reference to nutritionists at FHSC, ensuring home nutritional care and reducing the risk of hospital readmission. This work enabled the participation of 90% ( $n = 10$ ) of public hospitals ( $n = 11$ ) in the city that provide health care to adults. Public hospitals that provide care on specific areas, such as orthopedics, ophthalmology, infectious diseases, and maternity hospitals, were not included because discharge with enteral feeding is very unusual.

Also at the end of 2011, because new nutritionists joined the teams at FHSC and at the Municipal Health Department (MHD) of Belo Horizonte, the management of the Nutrition Division of the MHD requested a new project of a refresher course for nutritionists in charge of ENT.

The project submitted to FAPEMIG was approved, with funding released in early 2013. It included the following activities: a refresher course for newly hired nutritionists at FHSC; preparation of a handbook on Home Nutrition Therapy for Family Health Teams; development of distance education classes (DE), to be broadcast on Programa Telessaúde/UFGM for nutritionists at FHSC and in other cities and towns in Minas Gerais; and analysis of macronutrients and minerals from homemade enteral diets for domestic use prescribed by primary care services and partner hospitals in the municipality.

In mid-2013, after the results of the project were presented in regional seminars and national meetings, the General Coordination of Food and Nutrition (CGAN) of the Ministry of Health (MOH) proposed the extension of the project, with analysis of vitamins in the diets and expansion of teaching material for distance education. The agency believed that the problem of home enteral nutrition therapy that was experienced by nutritionists at FHSCs of Belo Horizonte occurs all over Brazil, and there was not enough educational content aimed at nutritionists working in Primary Care and Home Care. Thus, Phase II project was prepared. It was funded by the Ministry of Health through a Letter of Agreement with the Pan American Health Organization (PAHO).

The project is scheduled for completion in February 2015; therefore, this paper reports the results obtained so far in an attempt to contribute to other ongoing experiences.

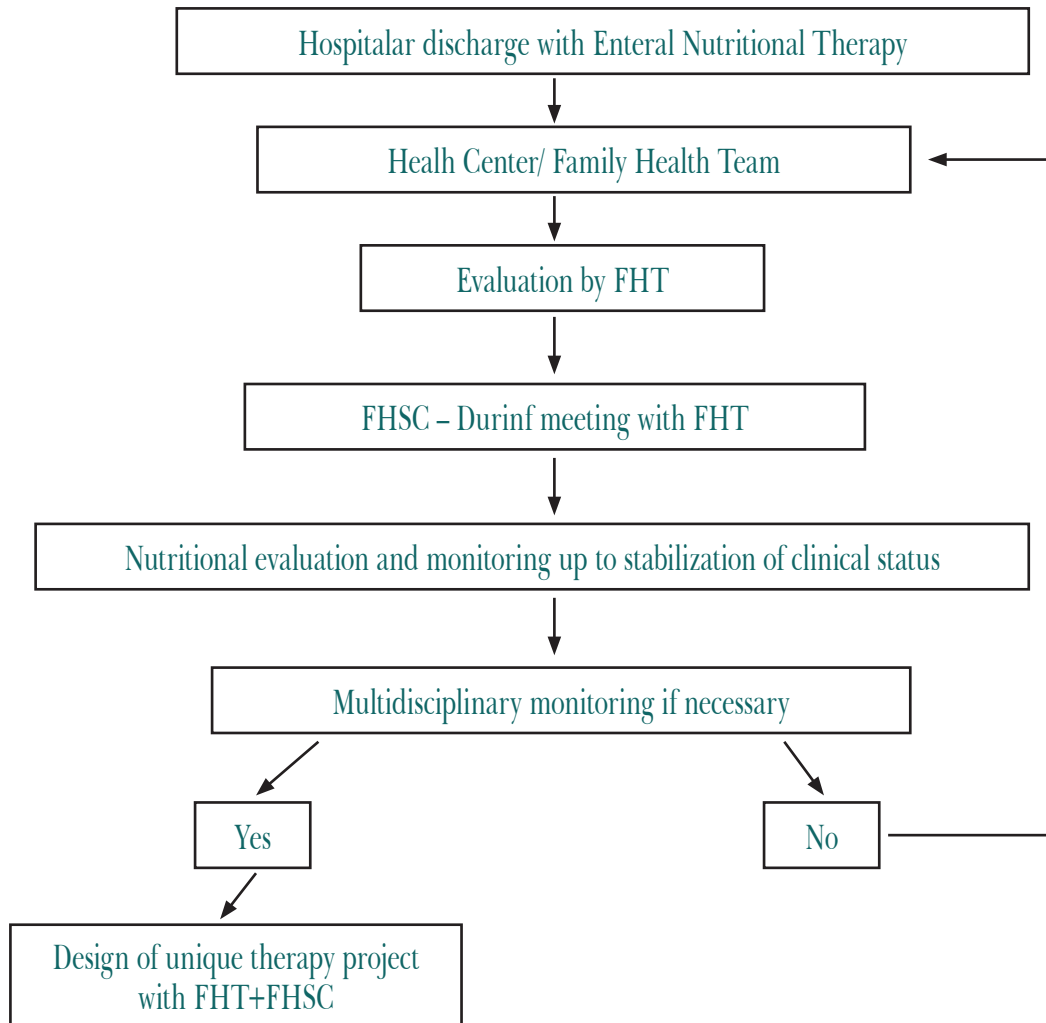
Undoubtedly, factors that foster the development of this project are the theme addressed, the amount of doubt and uncertainty about homemade diets prescribed after hospital discharges, the costs involved in inappropriate prescriptions and failure in recovery or stabilization of patients under ENT. However, the study proposal of homemade hospital diets did not have the participation of all the hospitals, because of fear of losing autonomy or imposition of one or another diet when discharge was prescribed. Throughout awareness-raising, it was always made clear that the group did not intend to impose hospital discharge diets, but knowledge of the chemical composition of the currently prescribed diets, it is possible to propose formulas with better composition and have awareness of nutrients that may have to be supplemented.

## Results

### Flowchart for referral of patients under ENT

The first activity of the working group was the development and establishment of a reference flow (Figure 1), between the hospitals involved in the project and FHSC. The flow established that every resident of Belo Horizonte after hospital discharge (from hospitals of the group), under alternative nutrition and enteral diet, should be referred to a reference Basic Health Unit (BHU) holding a discharge report with information on nutrition history. Social Services of the hospital or the nutritionist responsible for prescribing the discharge diet will contact Social Services of the BHU or the reference FHSC and advise on the need for home visits for clinical and nutritional counseling. It was established that the first home visit will be made by FHT, which prompts the follow-up by the nutritionist from the reference FHSC. A multidisciplinary follow-up will be established if needed.

This flow allowed the development of an incipient health care network where requests and commitments are agreed. According to Mendes (2008),<sup>25</sup> this agreement occurs because there is encouragement of health production, autonomy and acknowledgment of agents participating in the process, the sustainability of the process.



**Figure 1.** Flow of referral of patients under ENT.



## Refresher course for nutritionists at FHSC

The establishment of the flow of referral of patients under ENT required professional development of nutritionists at the FHSC of MHD, because they had skills and competencies acquired throughout their undergraduate or professional experience in hospital clinical nutrition, rather than practical experience in Primary and Home Care. Thus, two 30-hour training courses were held. The first one, in 2010, was attended by 41 nutritionists; the second course is still in progress and is scheduled for completion in October 2014, with attendance of 27 nutritionists at FHSC.

There was a staff turnover in 2012/2013; new jobs were created and temporary staff were hired on a regular basis. For this reason, only 15.1% (n = 8) of nutritionists trained in 2010 remained in the network. Thus, 100% (total population = 41) of the nutritionists at FHSC were trained in the first phase and 50.9% (total population = 53) in the second. At the end of the second refresher course, therefore, 66.0% (n = 35) of the nutritionists at FHSC-BH will have been trained in the management of patients under home enteral nutrition.

The approach of this refresher course involves in-person meetings at the School of Nursing at the Federal University of Minas Gerais, and a multidisciplinary approach. The proposed topics are taught by doctors, nurses, pharmacists, psychologists and nutritionists from partner hospitals and from FHSC. The main issues discussed were associated with provision of care to individuals, preparation and manipulation of diets, careful handling of feeding tubes and control of complications. In addition to theoretical discussions, the teaching methodology includes case studies and simulations in laboratories of nursing practice and dietary techniques .

Homemade diets for routine discharge orientation of public hospitals involved in the project were prepared in the dietetics laboratory by nutritionists at NAS, with the support of these researchers and scholarship students of the project . Then, fluidity and viscosity tests were conducted by administering diets by the gravitational method, using 20ml syringes, and by 12 ml nasoenteric and nasogastric tubes for adults. The stability of the diets was also verified by visual inspection of the phase separation process in 12-hour storage.

After the first training course in 2010, nutritional assessment techniques and other topics related to nutrition activities in primary care were discussed, addressing questions and difficulties in prescribing homemade diets. In addition, these professionals were monitored through continued discussion of cases with technical assistance in nutrition by the Municipal Health Department. The impact of the refresher course currently in progress will be evaluated at the final seminar, which will take place in October 2014 and also in daily practice, together with nutrition experts at the Municipal Department of Health.

### Handbook with guidelines on home enteral nutrition therapy for caregivers

During the first refresher course for nutritionists, a handbook with guidelines on home ENT was designed with the help of all nutritionists participating in the project. The material was printed by the Municipal Health Department and delivered by nutritionists at FHSC to caregivers at the first home visit to patients under enteral feeding. The handbook contains information on types of diet, careful preparation of an enteral diet, conservation of diets, modes of administration of the diet, cleaning the tube, hydration of the patient, procedures in case of tube clogging, diarrhea, constipation, nausea and vomiting, gastric stasis and tube outlet. It also informs caregivers about medication administration and other procedures for patient care.

At the end of the handbook, a proposal is made for a handmade diet with formulations with 1,500, 1,800 and 2,100 kilocalories and a standard option as well as an option for hyperglycemia. The nutritionist should advise on the formulation to be followed. The proposed diet was developed by Esposito and colleagues,<sup>26</sup> and their chemical composition, analyzed by means of tables, meets many of the nutritional requirements for adult men 50-71 years.<sup>27</sup> Moreover, it is easy to prepare and has low cost (daily cost of BRL 5.57 for the standard 1.800Kcal diet and BRL 5.95 for the 1.800Kcal diet for hyperglycemia). This diet has been prescribed by two hospitals that are project partners and by FHSC in Belo Horizonte.

Although the handbook had not been tested before implementation on the network, the fact that most nutritionists responsible for delivery of the material in the household have participated or are participating in the training course in home enteral nutrition therapy enables them to clarify questions from caregivers and give them proper guidance. Thus, the handbook is a material to support caregivers, but not the only source of information about diet and its administration.

## Analysis of diets

Bromatological analysis has always been a major impediment for the safe administration of homemade enteral diets. The precise composition of such diets produced a great deal of doubt and debate, and this was an argument widely used by manufacturers of commercial enteral diets to advocate for discontinued use of homemade diets. It is argued that labels and legal aspects of commercial diets undoubtedly guarantee the content of nutrients and the harmony of the combination of these components. In homemade diets, in contrast, there would be less control of nutritional and microbiological quality.

Chemical analysis of the diets aims to provide professionals and users of home enteral nutrition therapy the use of highly specialized diets with defined composition. In addition, the preparation of technical files for easy understanding of preparation assists the efficient and safe use of regular home ENT.

Thus, 11 handmade diets prescribed after hospital discharge by eight public hospitals, in addition to the diet prescribed by FHSC, were studied for viscosity, stability, cost and technical preparation. Five out of them were selected for analysis because they met the criteria for a low cost, easy-to-prepare handmade diet, with no need to be sieved to prevent the retention of most of the nutrients, and with appropriate viscosity and stability, capable of being administered both with the aid of a 20 ml syringe) and by the gravitational method, by a 12ml nasogastric or nasoenteric tube.

Proximate analysis of macronutrient composition was performed by traditional analytical methods recommended by the *Association of Analytical Chemists*, and analysis of minerals was made by atomic emission spectrometry. Globally, macronutrients were appropriate and there was a low amount of fiber, copper, magnesium and manganese. Three diets showed high amount of sodium. The other minerals were in adequate amounts compared to the recommendations for men aged 50 to 71 years.<sup>27</sup> The detailed results of these analyses are being published in another paper of this volume. The suitability of sodium has been performed and that of other minerals and fiber is being studied.

Vitamins and osmolality are to be analyzed. After the completion and evaluation of the results of the analyses, new diets will be proposed and disseminated through distance education classes and publications.

The next two activities are still in progress; thus, they will be briefly described to provide information on the whole project.

## Preparation of the Technical Handbook on Home Enteral Nutrition Therapy

The preparation of the *Technical Handbook on Home Enteral Nutrition* is important for establishing protocols based on the literature and on technical-scientific knowledge, in order to standardize the steps of nutritional care to patients under home NT. Thus, the creation of a support tool for nutritionists was intended to provide autonomy to nutritionists at FHSC and professionals of Family Health Teams in the development of procedures for patient care under ENT, to ensure the continuity and completeness of health care to these individuals.

The objective of the handbook is to provide scientific and technical reference information for primary care professionals, as well as standardize nutritional care to patients under home ENT. It is being developed with the participation of professionals who taught classes at the training courses for nutritionists, under the supervision of these researchers.

Copies will be printed for the nutritionists at FHSC, the Family Health Teams, with one copy being delivered to each team of Basic Health Units (BHU) and each team of Home Care Program (HCP) of Belo Horizonte.

## Preparation of digital learning material for Distance Education (DE)

A proposal was made to prepare educational material for distance education because it was believed that the problem of home ENT experienced by nutritionists at FHSC in Belo Horizonte was probably bigger in small and midsize cities in Minas Gerais and Brazil. Moreover, there was a lack of content available for nutritionists at FHSC in Programas de Telessaúde at UFMG. Therefore, the objective was not only create materials that could make up for the physical distance of the learning environment, but also creating a media set where contents are presented in a dialogical and contextualized manner, thus encouraging meaningful learning.

It will be made available in electronic media, together with video demonstration of handling and preparation of homemade enteral diets, including recipes, preparation files and information on nutritional value. It will also include guidelines that must be passed on to caregivers, such as administration of diet, careful handling of feeding tube, hygiene, preservation of homemade diet, hydration, problem situations (diarrhea, vomiting, stasis, nausea, tube outlet, etc.), plus practical ENT situations experienced by nutritionists at FHSC in Belo Horizonte, in order to contextualize and discuss problems faced at households.

The material will be sent to CGAN/MS to be broadcast on RedeNutri, thus improving the skills of nutritionists at FHSCs all over Brazil.

## Perspectives

The project strengthens the relationship between the university and managers and professionals in the health care system in order to improve nutritional care in Health Care Network in Belo Horizonte, in order to ensure the Human Right to Adequate and Healthy Food of patients under home enteral nutrition therapy.

This study accomplished to produce a flow of monitored referral of hospital discharge patients to primary care, as well as highly trained and skilled teams for the management and care of home enteral nutrition therapy. The project will contribute to the production and dissemination of scientific knowledge on the subject “handmade enteral diets”, which is still incipient literature, thus promoting practical training of professionals, both in undergraduate programs and in continuing education in the health services.

The experience developed in Belo Horizonte presents a methodology applicable to other municipalities, and the support of the Ministry of Health will contribute to sharing this experience, inducing the enhancement of care to individuals under home enteral nutrition therapy offered by SUS and strengthening the implementation of NFNP in Brazil .

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