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Reflections about the health literacy for home enteral nutritional therapy

Reflexões sobre o letramento em saúde para terapia nutricional enteral domiciliar

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ABSTRACT

The study sought to reflect on the use of health literacy principles in guiding caregivers of patients undergoing home enteral nutrition therapy. This is a descriptive, testimonial study. The orientation protocol adopted for caregivers was approached according to the fundamentals of health literacy regarding the development of educational materials. It was found that 41.2% of the topics in the health literacy principles were not covered. The main deficiencies were related to oral and written communication, lack of teach-back strategy, and texts requiring more years of schooling than recommended, with excessive instructions, making them difficult to understand and learn. The experience showed deficiencies in verbal and written communication, so it is essential that these deficiencies are corrected to properly operationalize home enteral nutrition therapy.

Keywords: Enteral nutrition. Caregivers. Health literacy.

RESUMO

O estudo buscou refletir sobre o uso dos fundamentos do Letramento em Saúde na orientação de cuidadores de pacientes em Terapia Nutricional Enteral Domiciliar. Estudo descritivo, do tipo relato de experiência. O protocolo de orientação adotado aos cuidadores foi abordado conforme os fundamentos do Letramento em Saúde, acerca da elaboração de materiais educativos. Foi observado que 41,2% de tópicos dos fundamentos do Letramento em Saúde não foram atendidos. As principais inadequações referem-se à comunicação verbal e escrita, na ausência da estratégia de teach back, bem como os textos demandavam mais anos de escolaridade que o recomendado, com instruções em excesso, dificultando compreensão e aprendizagem.

A experiência evidenciou falhas na comunicação verbal e escrita, assim, mostra-se fundamental que estas falhas sejam corrigidas para operacionalização adequada da Terapia Nutricional Enteral Domiciliar.

Palavras-chave: Nutrição Enteral. Cuidadores. Letramento em Saúde.

Introduction

Oral food intake can become insufficient, unsafe or unfeasible to meet individual nutritional needs when there is a pathology or a temporary or permanent situation. In this situation, enteral feeding, known as Enteral Nutritional Therapy (ENT), is used as the first alternative. The same therapy also integrates health care at home, when it is called Home Enteral Nutritional Therapy (TNED in Portuguese) (Brazilian Society of Parenteral and Enteral Nutrition [BRASPEN], 2018).

The demand for TNED is progressive (Brasil, 2014; BRASPEN, 2018), due to the following determining factors: the demographic transition, characterized by a more accentuated ageing population and its consequence on the type of care required; the epidemiological and nutritional transition, with an increase in the prevalence and incidence of cases of chronic non-communicable diseases, which can lead to physical, physiological and psychological disabilities, which also demand NEDT; the rise in hospital costs, leading to the search for less expensive alternatives, often including home care; the development of technologies that increase people's survival rate, including TNED; and the demand for greater privacy, individualization and humanization of health care, leading to the search for home care (Brasil, 2014; Cutchma, Eurich, Thieme & França, 2016).

Home care involves specific and complex actions and often the responsibility for this care falls on a family member, called a family caregiver, although this doesn't always mean a blood relative (Brasil, 2014; Bifulco & Levites, 2018), but rather the closest or most available person to carry out the care. Thus, the caregiver needs guidance on the care they will provide, guidance provided by the team accompanying the patient (Bicalho, Lacerda & Catafesta, 2008).

These guidelines must be properly understood to ensure the highest quality of care. In this context, the fundamentals of health literacy (HL), an educational strategy that empowers individuals with health information, stand out.

HL is defined as people's ability to access, understand, evaluate, and apply health information and to use health services to make judgments and decisions about health promotion and disease prevention and care (Sorensen et al., 2012). It is a concept that has been expanding, recognized as multidimensional, and which has come to value the communication skills of health systems with society. Thus, it implies how health infrastructure and policies, for example, may or may not facilitate the navigation, understanding and use of health information and services (Sorensen, 2019). On the other hand, the approach to this topic is relatively recent in Brazil and there are no publications focusing on the topic from the perspective of TNED and the caregiver responsible for it.

The aim of this study is to compare the TNED guidance provided by the staff of a hospital in the interior of Ceará - Brazil, with the fundamentals of HL for the development of written educational materials.

1 Methodology

This is a descriptive study, of the experience report type, carried out in a public tertiary hospital in the Cariri region of Ceará, located in the city of Juazeiro do Norte, 514 km from the state capital.

1.1 Participants

The study sample was made up of caregivers of patients who will be on NEDT and who have received nutritional advice on discharge from hospital.

1.2 Procedure

The experience reported covers the period from January 2013 to April 2017 and focuses on the educational actions of one of the authors of this study, who worked as a nutritionist in the Special Care Unit (SCU).

This SCU is intended for patients coming from the Adult Intensive Care Unit (ICU), Acute Stroke Unit or other care unit, usually with physical or neurological sequelae resulting from ischemic or hemorrhagic stroke or traumatic brain injury, dementia, and who are under some degree of palliation or require rehabilitation and weaning from devices (nasoenteral tube, tracheostomy, etc.).

It has 28 ward beds and one isolation room, which are attended by a specialized multi-professional team made up of a doctor, nurse, physiotherapist, nutritionist, speech therapist, social worker, pharmacist, psychologist and nursing technician. The vast majority of patients have a companion, who may be a family member or relative, or a person hired to accompany them during their hospital stay. One of the aims of the SCU is to prepare the future caregiver to continue caring for the patient at home.

1.3 Data collection

In general, discharge takes place within a maximum of 20 days of being admitted to the ECU. Once the need for TNED has been determined, specific discharge instructions are drawn up on an individual basis. The caregiver's stay in the unit makes it easier for them to understand the basic procedures they will have to adopt at home.

The discharge orientation, aimed at future caregivers who had already been defined by the patients or their families, was carried out in the SCU itself, in groups of 5 to 15 people. The activity consisted of an oral and dialogued presentation, lasting approximately 50 minutes, at which point the reports and guidelines were also handed out in printed form. The printed material comprised 04 pages. The guidance was given only once to each caregiver.

Its content included: an explanation of why the patient needed enteral feeding; explanations of the reports for industrialized enteral diets and also the dietary prescription for preparing homemade enteral diets; a list of the materials needed to administer the enteral diet at home; instructions on handling and preparing homemade enteral diets; the administration of any type of diet and the management of the tube after administering the diets. Any questions were answered at this time or during the patient's stay in hospital.

The doubts raised by the future caregivers made it clear that there was a need for an approach with visual information on the materials to facilitate understanding. We then added to the theoretical explanation the display of the materials that the caregivers would use: industrialized enteral nutrition packaging, macro-drop tube, enteral nutrition bottle, and 60 ml syringe. This orientation process for NEDT was not based on health literacy principles.

1.4 Data analysis

An analysis was therefore carried out, initially considering oral communication. To this end, we considered the theoretical framework of Abrams, Rita and Nielsen (2012), regarding the use of teachback, i.e. checking speech comprehension not through questions that allow a yes or no answer, but by asking the target group to repeat the explanation in their own words.

As for written communication, the material was analyzed according to a compilation by various authors, carried out by Vasconcelos, Sampaio and Vergara (2018). The following aspects were prioritized:

a) In terms of content and language: Preparing the text for a school level from 5th to 8th grade. grade, depending on the target audience; Consider cultural issues, emotions and reactions of the target group of the educational action; Clear purpose of the material; Maintain a conversational style (2nd person) and active voice; Use common and short words (1 to 3 syllables); Use short sentences, with a maximum of 15 words and/or 20 to 60 characters; Use a single idea per sentence; Provide information based on the needs of the target audience; Information given in the sequence in which it will be used by the audience; Provide the most important information at the beginning; Present concepts and actions in a logical order; Avoid patronizing or judgmental language; Contextualize the topic before new information; Focus information on behaviors and always emphasize positive actions (what you should do) rather than negative ones (what you shouldn't do); Avoid using jargon or abbreviations (if you do, explain them); Give examples for abstract ideas and concepts and use them minimally; Focus on one piece of information at a time, up to 3 to 4 central pieces of information per document or section; Use up to 5 items per list; Always present a summary of the important points.

b) Regarding images and illustrations: Avoid using a table or chart; As for form or presentation: Font size 12 or 14 and 14 or 16 for the elderly and people with impaired vision; Use bold subheadings or bullets; Use serif font; Avoid using capital letters or italics; Use bold and underline for necessary emphasis; Use black font color and use other colors with caution; Subheadings with a font two points larger; Minimum space of 2. 5 cm between page margins and between columns of text; Do not use symbols or images, expressions and/or recommendations that could cause controversy; Include date of publication and authors' names; White, non-glossy paper and good contrast between font and background color; Do

not use quotes from research, experts in the field, or statistics; Space above headings and subheadings should be greater than below; Minimum space between lines 1. 5; Present the complete idea on one page or on both sides of the sheet; Avoid appeals and recommendations that tend to create demands that cannot be met; Include resources that lead to active participation by the reader.

2 Ethical considerations

Since this is an experience report, the study did not need to be approved by a research ethics committee. However, it complied with all the considerations for its conduct set out in Resolution 466/2012 of the National Health Council.

3 Results

Considering oral communication and the teach-back principles proposed by Abrams, Rita and Nielsen (2012), it can be seen that the training carried out did not include this point, since the questions asked at the end of the topics were generally of the type: "Did you understand?" or "Do you have any questions?", with the only possible answers being yes or no.

Regarding the written material, Table 1 shows the comparative analysis between the guidelines based on health literacy and those provided by the service.

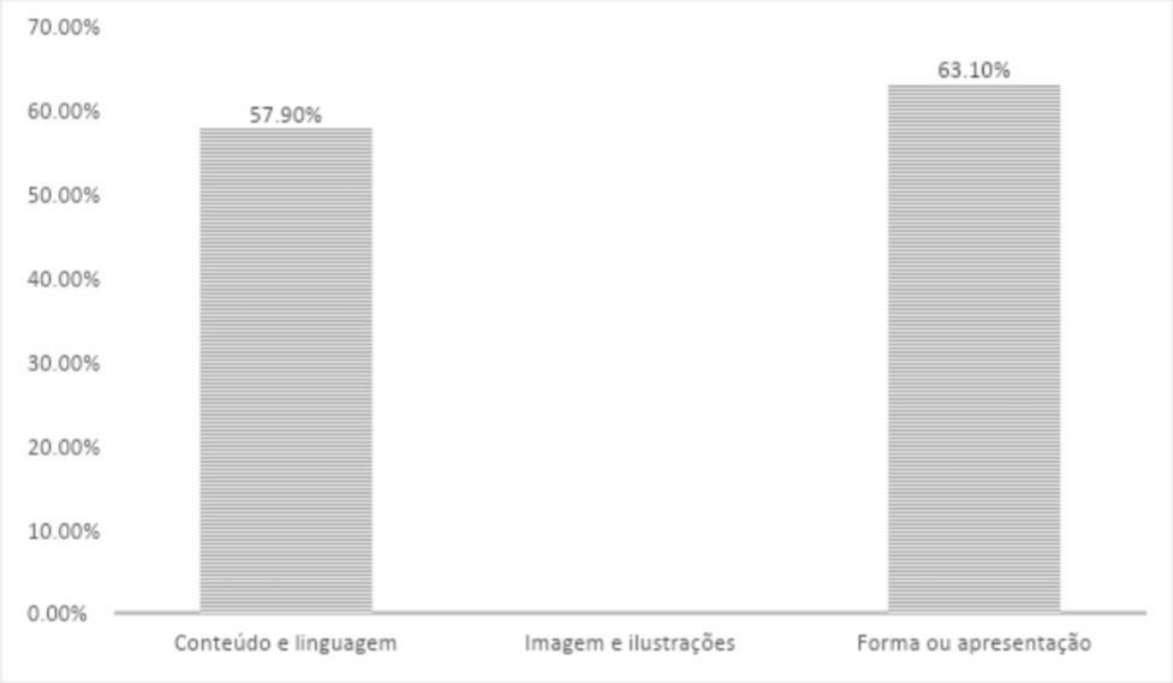
Figure 1 therefore shows the percentage of compliance of the material used with the HL guidelines, according to the 3 categories assessed: content and language; images and illustrations; and form or presentation. Analysis of the document without this stratification shows that 58.8% of the recommendations were met.

Table 1. Compliance with Health Literacy (HL) guidelines for the development of written materials for the discharge guidance protocol for patients undergoing enteral nutritional therapy at the hospital. Fortaleza, Ceará, Brazil, 2020.

Health literacy guidelines - content and language	**Compliance to the guideline**
The text is aimed at a schooling level equivalent to 5th-8th grade.	No
It considers cultural issues, emotions, and perspectives of the target group.	Yes
The purpose of the material is clear.	Yes
It uses conversational style (2nd person) with active voice.	No
Words are common and understandable. 1 to 3 syllables.	No
Sentences are clear, with up to 15 words or 60 characters.	No
One idea per sentence is provided.	Yes
Information is based on the audience's needs.	Yes
Information is given in the sequence it will be used.	Yes
The most important information is placed at the beginning.	Yes
Concepts and ideas are presented logically.	No
Patronizing or judgmental language is not used.	Yes
The theme is contextualized before new information.	Yes
Information focuses on behaviors, emphasizing positive behaviors (what should be done) rather than negative ones (what should not be done).	Yes
The use of jargon or abbreviations is avoided (or explained).	Yes
Abstract concepts are minimized.	Yes
There are 3 to 4 central pieces of information per document or section.	No
Up to 5 items are used per list	No
Present a summary of the important points	No
Health literacy guidelines - Images	**Compliance to the guideline**
Avoids the use of schematic diagrams and tables	No
Health literacy guidelines - Presentation	**Compliance to the guideline**
- Font size minimum 12 or 14 if for elderly people and those with visual impairments.	No
- Use the same font for letters or at most two styles.	Yes
- Use bold or bullet points for subtitles.	Yes
- Use a serif font.	No
- Avoid the use of all capital letters.	No
- Avoid italics.	Yes
- Use bold and underlining for emphasis.	Yes
- Use black ink, and if other colors, use them cautiously.	Yes
- Use subtitles with a font size two points larger.	Yes
- Utilize at least 2.5 cm spacing between page margins and between text columns.	Yes
- Do not use symbols, images, expressions, and/or recommendations that could provoke controversy.	Yes
- Include the publication date and authors' names.	No
- Use white, non-glossy paper, ensuring contrast between the text color and the paper background.	Yes
- Do not use research citations, area specialists' quotes, or statistics.	Yes
- Space above titles and subtitles is larger than below.	No
- Minimum line spacing is 1.5.	No
- Present a complete idea on one page or both sides of the sheet.	Yes
- Avoid appeals and recommendations that could create demands that cannot be met.	Yes
- Incorporate features that encourage active participation from the reader.	No

Source: Adapted from Vasconcelos, Sampaio and Vergara (2018).

Figure 1. Percentage of compliance with the guidelines of Health Literacy (HL), by the discharge guidance protocol for patients on enteral nutritional therapy at the hospital, according to the category evaluated.



Source: prepared by the authors.

4 Discussion

Considering the concept of health literacy (Sorensen *et al*., 2012), and the importance of communication in the process of understanding health education actions (Marques & Lemos, 2017; Machado, Dahdah & Kebbe, 2018), it can be seen that the discharge guidance for NEDT given to caregivers has flaws that can prevent the proper operationalization of the procedures that should be adopted by this target audience.

Although most of the HL recommendations have been met, those that have not are relevant in the process of empowering the target audience.

Although there is no scale of weights for the HL items, we understand that there are some that have a greater impact than others.

The first thing to mention is the non-use of teach-back in oral communication. The purpose of the method is to encourage the audience to describe in their own words what they have understood from the training (Abrams, Rita and Nielsen (2012), which is an important moment for the professional to realize the main difficulties and reinforce the guidance to overcome them. A study by Abianeh, Zargar, Amirkhani and Adelipouramlash (2020) shows that the application of self-care training based on the teach-back

method produced a significant difference in the quality of life of hemodialysis patients, recommending its use by the care team. In Brazil, the use of teach-back is already explicitly encouraged by the Brazilian Society of Cardiology (2020), although it is difficult to find when searching directly on the Society's website. This approach strategy is not mentioned in the Brazilian Guidelines for Home Nutritional Therapy, stating only that discharge guidelines for NHND should be adjusted to the profile of the target population (BRASPEN, 2018).

The main written recommendation that was not complied with according to the HL principles, and which will have the greatest negative impact on the learning process regarding the proper management of NEDT, is in the area of content and language, which deals with the amount of information passed on in a single training session, and which recommends not exceeding 4 pieces of information at a time. The experience reported here showed that at least 12 different topics on NEDT were covered in a single 50-minute meeting.

Authors suggest that when it is not possible to reduce the number of topics, written information should be reduced and visual information combined (OSBORNE, 2013; Vasconcelos, Parente & Sampaio, 2019).

Thus, reorganizing the orientation, dividing the topics into separate meetings, would help to ensure that the proposed content is better assimilated. We would like to point out some difficulties that the service will need to overcome to implement this proposal, which are the constant changes of caregivers and how to follow up the training sessions, as well as the organization of the nutritionist's daily activities in order to provide more days for guidance to future caregivers. One strategy could be to use videos or podcasts, each containing fewer messages, which the individual could listen to as many times as necessary, until any doubts arise (Tackett *et al*., 2018; Ramos, Pereira & Silva, 2019).

The way people communicate is undergoing transformations influenced using technology and social networks, making them attractive and popular. Thus, far beyond communication through writing or speech, the use of video has invaded the context of health education through the specific language, sounds and images of everyday life, and its importance is increasingly recognized (Griffis *et al*., 2014; Jamal *et al.*, 2015; Knuppel, 2019). The development of videos as a proposed technological tool for health education is pertinent in this context of a population with low levels of health literacy.

The transfer of information is facilitated using videos, even among non-literate persons (National Academy of Sciences, Engineering and Medicine, 2016).

Thus, to overcome the inadequacies perceived in the highly rated guidance document, the use of videos is suggested. Pintão (2019) states that video production is emerging as a current trend. Of course, face-to-face contact with the team cannot be dispensed with. A team that uses teach-back and produces a set of videos with up to 4 messages in each, could be more successful in empowering the target audience. The videos would be presented and discussed and, once at home, could be accessed indefinitely, until the next scheduled contact with the health team.

Another important point detected is the use of language that requires a higher level of education, yet another factor that prevents the content from being satisfactorily assimilated. The recommendation is to use more accessible, simple and clear language, replacing technical terms and requiring a level of education between 5th and 8th grade, thus making it more attractive and understandable to the intended audience, generating greater patient adherence, satisfaction and autonomy (Zarcadoolas, Pleasant & Greer, 2006; Osborne, 2013; Vasconcelos *et al.,* 2019).

Also at odds with the fundamentals of health literacy is the use of tables in the discharge guidance protocol for NEDT applied by the institution. However, even though their use is not recommended (Vasconcelos *et al*., 2019), for the profile of the public served, which has a low level of education, we believe that the best way to present information on the type and volume of enteral diet, as well as times of use, is to use tables. On the other hand, the tables can be reorganized to make them clearer, while complying with the other HL fundamentals.

The American Institute of Medicine, in its report on SL, pointed out almost three decades ago that inadequate SL is not a problem for the patient, or caregiver in our case, but a challenge for the healthcare team that deals with this public (Kirsch, Jungeblut, Jenkins & Kolstad, 1993). This means that it's the health professionals who need to find ways out of successful education/training.

Home care, and in particular managing TNED, requires acquiring the knowledge needed to properly operationalize this care.

The experience reported here revealed deficiencies in oral and written communication that need to be corrected, particularly the lack of use of teach-back, excessive written content, and writing that requires more years of schooling to understand. It is essential that these deficiencies are corrected to achieve the proper operationalization of TNED.

Final considerations

With this study, we believe we are contributing to the dissemination of health literacy and the impact of its use in health education. In this way, old health education practices can be rethought and based on health literacy so that care is effective. A limitation of this study is the fact that only one health education practice was analyzed, which may not correspond to the practice adopted in other hospital units, thus encouraging future studies to elucidate the subject.

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