

## Educative practices with families of children and teenagers under oral antineoplastic chemotherapy: an integrative review

*Práticas educativas junto às famílias de crianças e adolescentes em quimioterapia antineoplásica oral: revisão integrativa*

*Prácticas educativas con familias de niños y adolescentes en quimioterapia antineoplástica oral: revisión integrativa*

### ABSTRACT

**Objective:** This study aims to analyze, in the scientific productions, the educational practices used to guide family members and caregivers of children and adolescents with cancer regarding the oral antineoplastic chemotherapy treatment. **Method:** Integrative literature review available in the LILACS via VHL, SCIELO, CINAHL, PUBMED, and EMBASE databases, conducted in September 2020. Original articles that addressed the topic were included. Those that focused on educational practices directed to professionals, adult patients, and other types of chemotherapy were excluded. **Results:** The sample consisted of five international articles. The evidence was grouped according to the type of educational practice: clinical consultation, group guidance with dynamics, home maintenance program, and production of printed educational materials. **Final considerations:** Health education is essential in the preparation of family members of children and adolescents undergoing oral antineoplastic chemotherapy and the nursing team must develop training and guidance that promotes a comprehensive, safe and resolute care.

**Descriptors:** Child; Family; Health Education; Antineoplastic Agents; Oral Administration; Nursing.

### RESUMO

**Objetivo:** Analisar, nas produções científicas, as práticas educativas empregadas para orientação dos familiares e cuidadores de crianças e adolescentes com câncer quanto ao tratamento quimioterápico antineoplásicos orais. **Método:** Revisão integrativa da literatura disponível nas bases de dados LILACS via BVS, SCIELO, CINAHL, PUBMED e EMBASE, realizada no mês de setembro de 2020. Foram incluídos artigos originais que abordassem a temática. Excluíram-se aqueles que focavam práticas educativas direcionadas a profissionais, pacientes adultos e outros tipos de quimioterapia. **Resultados:** A amostra foi constituída de cinco artigos internacionais. As evidências foram agrupadas de acordo com o tipo de prática educativa: consulta clínica, orientações em grupo com dinâmicas, programa de manutenção domiciliar e produção de materiais educativos impressos. **Considerações Finais:** A educação em saúde é essencial no preparo de familiares de crianças e adolescentes em quimioterapia antineoplásica oral e a equipe de enfermagem deve desenvolver treinamentos e orientações que promovam um cuidado integral, seguro e resolutivo.

**Descritores:** Criança; Família; Educação em Saúde; Antineoplásicos; Administração Oral; Enfermagem.

### RESUMEN


**Objetivo:** Analizar, en las producciones científicas, las prácticas educativas empleadas en la orientación de las familias y de los cuidadores de niños y adolescentes con respecto al tratamiento con quimioterapia antineoplásica oral. **Método:** Revisión integradora de la literatura disponible en las bases de datos LILACS vía BVS, SCIELO, CINAHL, PUBMED y EMBASE logadas en el mes de septiembre de 2020. Fueran incluidos artículos originales que abordaron el tema. Se excluyeron los que eran centrados en prácticas educativas dirigidas a profesionales, pacientes adultos y otros tipos de quimioterapia. **Resultados:** La muestra se constituyó de cinco artículos internacionales. Las evidencias fueran agrupadas de acuerdo con el tipo de práctica educativa: citas clínicas, orientaciones grupales con dinámica, programa de atención domiciliar y producción de materiales educativos impresos. **Consideraciones finales:** La educación en salud es esencial en el preparo de las familias de niños y adolescentes en tratamiento con quimioterapia antineoplásica oral y el equipo de enfermería debe desarrollar capacitaciones y pautas que promuevan una atención integral, segura y resolutiva.

**Descritores:** Niño; Familia; Educación en Salud; Antineoplásicos; Administración Oral; Enfermería.

Gabriele Alvernaz Silva Franco<sup>1</sup>

 [0000-0002-5456-531X](https://orcid.org/0000-0002-5456-531X)


Liliane Faria da Silva<sup>2</sup>

 [0000-0002-9125-1053](https://orcid.org/0000-0002-9125-1053)

Fernanda Garcia Bezerra Góes<sup>2</sup>


 [0000-0003-3894-3998](https://orcid.org/0000-0003-3894-3998)

Emília Gallindo Cursino<sup>2</sup>

 [0000-0002-5845-9709](https://orcid.org/0000-0002-5845-9709)

Juliana Rezende Montenegro

Medeiros de Moraes<sup>3</sup>

 [0000-0002-2234-6964](https://orcid.org/0000-0002-2234-6964)

Sandra Teixeira de Araújo

Pacheco<sup>4</sup>

 [0000-0002-4612-889X](https://orcid.org/0000-0002-4612-889X)

<sup>1</sup>Instituto Nacional do Câncer, RJ, Brasil.

<sup>2</sup>Universidade Federal Fluminense, RJ, Brasil.

<sup>3</sup>Universidade Federal do Rio de Janeiro, RJ, Brasil.

<sup>4</sup>Universidade do Estado do Rio de Janeiro, RJ, Brasil.

**Corresponding author:**

Gabriele Alvernaz Silva Franco

**E-mail:** [gabrielealvernaz@yahoo.com.br](mailto:gabrielealvernaz@yahoo.com.br)

### How to cite this article:

Franco GAS, Silva LF, Góes FGB, et al. Educative practices with families of children and teenagers under oral antineoplastic chemotherapy: an integrative review. Revista de Enfermagem do Centro-Oeste Mineiro. 2021;11:e4082. [Access\_\_\_\_\_]; Available in:\_\_\_\_\_. DOI: <http://doi.org/10.19175/recom.v11i0.4082>

## INTRODUCTION

Pediatric cancer is one of the leading causes of mortality in children and adolescents in developed countries and a public health concern<sup>(1)</sup>. In Brazil, it is the chronic disease with the highest mortality rate in the 0-19 year-old age group<sup>(2)</sup>, the expected number of new cases for each year of the triennium 2020-2022 will be 8,460<sup>(3)</sup>.

Pediatric cancer, unlike adult cancer, is predominantly embryonal in nature and usually affects the cells of the blood system and supporting tissues. It consists of a group of several diseases with their own characteristics regarding histopathology and clinical behavior, which have in common the uncontrolled proliferation of abnormal cells, the predominant types being leukemia (28%), central nervous system tumors (26%), and lymphomas (8%)<sup>(3)</sup>.

The various types of cancer are treated by associating or not, according to the case, five therapeutic modalities. In this review, we highlight the chemotherapeutic drugs that, in the treatment of pediatric cancer, contribute significantly to survival rates, because they are mostly chemosensitive<sup>(4)</sup>.

Chemotherapy treatment varies according to the diagnosis and cancer staging and can have four objectives: curative, adjuvant, neoadjuvant and palliative. The chemotherapy protocols can be composed of drugs administered orally, intravenously, intramuscularly, subcutaneously, intrathecally, intra-arterially, intracavitary, vesically, and topically, however, the intravenous is still the most used<sup>(4-5)</sup>.

For many years, the pharmacological treatment of cancer used exclusively intravenous antineoplastic therapy and health services were structured based on this treatment model. However, the pharmaceutical industry has been developing drugs with less aggressive toxic effects, which besides being well tolerated, are also easy to manage, the oral antineoplastic drugs<sup>(6)</sup>.

The oral antineoplastic is an important component in the treatment of several types of cancer such as pediatric acute lymphoblastic leukemia (ALL), central nervous system tumors, and in some palliative care protocols<sup>(7)</sup>.

There are advantages and disadvantages to this therapy. The advantages, on the one hand, refer to the elimination of the need for the use of Central Venous Catheter (CVC). Even with all the benefits that the use of catheters brings to the treatment of children and adolescents, it should be noted that catheters are invasive and therefore not free of complications. Complications can be of infectious or non-infectious origin, such as deep vein thrombosis, reservoir extrusion, rupture, embolization and obstruction, besides the activation being a factor of pain, fear and stress in children<sup>(8)</sup>.

Other advantages of the oral antineoplastic treatment refer to the convenience of performing the treatment in the home environment, thus allowing the child or adolescent to spend more time with the family and less time in hospitals, which generates a strong impact on quality of life<sup>(5-6)</sup>.

The disadvantages, on the other hand, are the variations in the absorption of the therapeutic dose; the risk of accidents with overdose; the need for effective self-care; and the difficulty in managing adverse effects. These aspects can increase the risk of non-adherence to oral therapy and cause harmful effects on healthy individuals who regularly take these medications<sup>(3-4)</sup>. Studies have pointed out variations in adherence among children and adolescents because of the different social and family contexts in which they are inserted, medication adherence may be particularly low among certain socio-demographic groups such as those with low income, low maternal education, and among adolescents and young adults<sup>(7,9)</sup>.

Thus, with the growing supply of oral antineoplastic drugs, the development and reorganization of educational practices aimed at self-care, directed at family members of children and adolescents with cancer involving the administration of such drugs were perceived as relevant; since the action and effectiveness of oral antineoplastic drugs at home depend on the efficiency of self-care<sup>(6)</sup>.

Health educational practices, from a dialogical and emancipatory perspective, enable human autonomy as the person responsible for their own trajectory of health and disease. In this sense, the nursing team plays a significant role in the promotion of self-care when it expands its care and educational practices to the family, caregivers, and to the patient himself, whether adult or pediatric, enabling him to face chemotherapy therapy and the problems that may arise during treatment. For the educational practices to take place, it is necessary to know the best strategies of educational approach, to recognize potentialities to increase the capacity of family members to perform self-care actions<sup>(10-11)</sup>.

The use of oral antineoplastic drugs at home can be complex and requires family members and caregivers to face new challenges, as they become responsible for the administration and self-management of symptoms and adverse effects, and also for treatment compliance<sup>(12)</sup>. The orientations are primordial for the continuity of care for children and adolescents undergoing chemotherapy, because they provide the reduction of the consequences of adverse effects and toxicities, improving adherence to treatment with oral antineoplastic drugs and, consequently, providing a better quality of life<sup>(13)</sup>.

Thus, it is the role of the nurse, during the nursing consultation and during the discharge process, to guide family members and caregivers of children and adolescents regarding the best time for medication administration, drug interactions, adverse effects, safe handling of the drug, storage and disposal, and when it is necessary to seek care at the hospital unit for complications arising from the therapy<sup>(13)</sup>.

Thus, considering the scarcity of studies associated with the repercussions of oral antineoplastic drugs on the lives of children, adolescents, and their families, it is important to identify studies that address the educational

practices directed at these clients, which can help nurses optimize their actions to better serve them.

From this perspective, the present study aimed to analyze in the scientific productions, the educational practices used to guide family members and caregivers of children and adolescents with cancer regarding the oral antineoplastic chemotherapy treatment.

**METHODS**

This is an Integrative Literature Review (ILR), one of the research methods used in Evidence-Based Practice (EBP), which provides an opportunity to synthesize scientific data on a given research problem and the applicability of the results in clinical practice. To conduct the IR, 6 distinct steps were developed, similar to the stages of conventional research development: (a) formulation of a hypothesis or definition of the research question; (b) identification, in the databases, of studies that would be included in the review and establishment of inclusion and exclusion criteria; (c) selection of the research that composed the review sample; (d) evaluation of the included studies; (e) interpretation of the results and synthesis of the data and (f) presentation of the main results evidenced from the analysis of the included articles<sup>(14)</sup>.

For the development of the research question, the PICO strategy was used<sup>(14)</sup>: P

(Population) = families/caregivers of pediatric cancer patients; I (Intervention) = health education strategies/practices for patient care; Co (Context) = treatment with oral antineoplastic drugs. From this perspective, the question was, "What health educational strategies/practices have been carried out for the guidance of family members/caregivers of children and adolescents with pediatric cancer undergoing treatment with oral antineoplastics?"

The survey of studies in the literature was carried out in September 2020, in the following informational resources: Latin American and Caribbean Literature on Health Sciences (LILACS) via Virtual Health Library (VHL); Scientific Electronic Library Online (SCIELO); Medical Literature Analysis and Retrieval System Online (MEDLINE), via PubMed; Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Evidence-Based Medicine (EMBASE).

The operationalization of this research began by consulting the Health Sciences Descriptors (DeCS), through the VHL, the Medical Subject Headings (MeSH), of the National Library, the (EMTREE) of EMBASE and the CINAHL title. The choice of descriptors and their synonyms was made in order to capture as many of the available articles as possible. The search terms used, combined with Boolean operators, are exemplified in the search strategy in the information resources (Chart 1).

Figure 1 – Search strategies of studies related to the theme, in information resources, through the association of descriptors. Niterói, RJ, Brazil, 2020.

Database	Acronym	Search strategy	Results
MeSH Terms PubMed	P	<i>((Family[mj] OR Family[tiab] OR caregivers[mj] OR caregivers[tiab] OR Parents[mj] OR Parents[tiab]) ((Child[mj] OR Child*[tiab] OR Adolescent[mj] OR Adolescent*[tiab] OR Child, preschool[mj] OR Preschool child[tiab] OR Teen*[tiab] OR Pediatrics[mh] OR Pediatric*[tiab] OR Paediatric*[tiab])) AND</i>	
	I	<i>(Patient Education as Topic[mh] OR "Patient Education as Topic"[tiab] OR Education[mj] OR Education[tiab] OR educational practice*[tiab] OR Health education[mj] OR Health education[tiab] OR Orientation[mj] OR Orientation[tiab])) AND</i>	422
	Co	<i>(Chemotherap*[tiab] OR Drug Therapy[mj] OR Drug therap*[tiab] OR Oral Drug Administration[mj] OR Oral Drug Administration[tiab] OR Antineoplastic Agents[mj] OR Antineoplas*[tiab]))</i>	
EMTREE EMBASE	P	<i>('family'/mj OR 'family':ti,ab OR 'caregiver'/mj OR 'caregiver':ti,ab OR 'caregivers':ti,ab OR 'family caregiver':ti,ab OR 'family caregivers':ti,ab OR 'parent'/mj OR 'parent':ti,ab OR 'parents':ti,ab) ('child'/mj OR 'child':ti,ab OR 'children':ti,ab OR 'adolescent'/mj OR 'adolescent':ti,ab OR 'teenager':ti,ab OR 'preschool child'/mj OR 'child, preschool':ti,ab OR 'pre-school child':ti,ab OR 'preschool child':ti,ab OR 'childhood'/mj OR 'childhood':ti,ab OR 'pediatrics'/mj OR 'paediatric care':ti,ab OR 'paediatric educating':ti,ab OR 'paediatric education':ti,ab OR 'pediatric care':ti,ab OR 'pediatric educating':ti,ab OR 'pediatric education':ti,ab OR 'pediatrics':ti,ab OR 'pediatrics department':ti,ab OR 'pediatry':ti,ab) AND</i>	
	I	<i>('patient education'/mj OR 'education, patient':ti OR 'patient education':ti OR 'patient education as topic':ti OR 'education'/mj OR 'education':ti OR 'educational practice*':ti OR 'health education'/mj OR 'education, health':ti OR 'health education':ti OR 'orientation'/mj OR 'orientation':ti) AND</i>	139
	Co	<i>('chemotherapy'/exp OR 'chemotherapeutics':ti,ab OR 'chemotherapy':ti,ab OR 'drug therapy'/exp OR 'drug therapy':ti,ab OR 'drug treatment':ti,ab OR 'therapy, drug':ti,ab OR 'treatment, drug':ti,ab OR 'oral drug administration'/exp OR 'drug administration, oral':ti,ab OR 'oral drug administration':ti,ab OR 'oral drug intake':ti,ab OR 'drug administration'/exp OR 'administration, drug':ti,ab OR 'drug administration':ti,ab OR 'antineoplastic agent'/exp OR 'anti cancer drug':ti,ab OR 'anticancer drug':ti,ab OR 'antineoplastic agent':ti,ab OR 'antineoplastic agents':ti,ab OR 'antineoplastic drug':ti,ab OR 'antineoplastics':ti,ab OR 'antitumor drug':ti,ab OR 'antitumour drug':ti,ab OR 'cancer chemotherapeutic agent':ti,ab OR 'drug, antineoplastic':ti,ab OR antineoplas*:ti,ab)</i>	

(continue)

Database	Acronym	Search strategy	Results
Títulos CINAHL	P	<i>(TI((Family OR caregiver* OR Parent*)) OR ((Child* OR Adolescent* OR Preschool child* OR Teen* OR Pediatric* OR Paediatric*)) AND</i>	16
	I	<i>(("Patient Education as Topic" OR Education OR educational practice* OR Health education* OR Orientation)) AND</i>	
	Co	<i>(Chemotherap* OR Drug therap* OR "Oral Drug Administration" OR Antineoplastic Agent* OR Antineoplas*))</i>	
DeCS LILACS	P	<i>('Família' OR 'Family' OR 'Familia' OR 'Cuidadores' OR 'Caregivers' OR 'Cuidadores' OR 'Pré-escolar' OR 'Child, Preschool' OR 'Preescolar' OR 'Adolescente' OR 'Adolescent' OR 'Adolescente' OR 'Criança' OR 'Child' OR 'Niño' AND</i>	71
	I	<i>('Educação em saúde' OR 'Health Education' OR 'Educación en Salud' OR 'Promoção da saúde' OR 'Health Promotion' OR 'Promoción de la Salud' AND</i>	
SCIELO	Co	<i>('Neoplasias' OR 'Neoplasms' OR 'Neoplasias' OR 'Tratamento Farmacológico' OR 'Drug Therapy' OR 'Quimioterapia' OR 'Antineoplásicos' OR 'Antineoplastic Agents' OR 'Antineoplásicos' OR 'Administração Oral' OR 'Administration, Oral' OR 'Administración Oral'</i>	11

Source: Research data.

To select the articles, the titles and abstracts were read observing the following inclusion criteria: original articles that addressed the educational strategies/practices for the population of families of children and adolescents on oral chemotherapy. We excluded secondary studies that did not meet the scope of this integrative review, which directed the educational practices to professionals or adult patients, and also other types of chemotherapy. There was no limitation as to the year or language of publication of the articles, because it was perceived a restriction in the number of publications related to the theme when a certain period of time was selected.

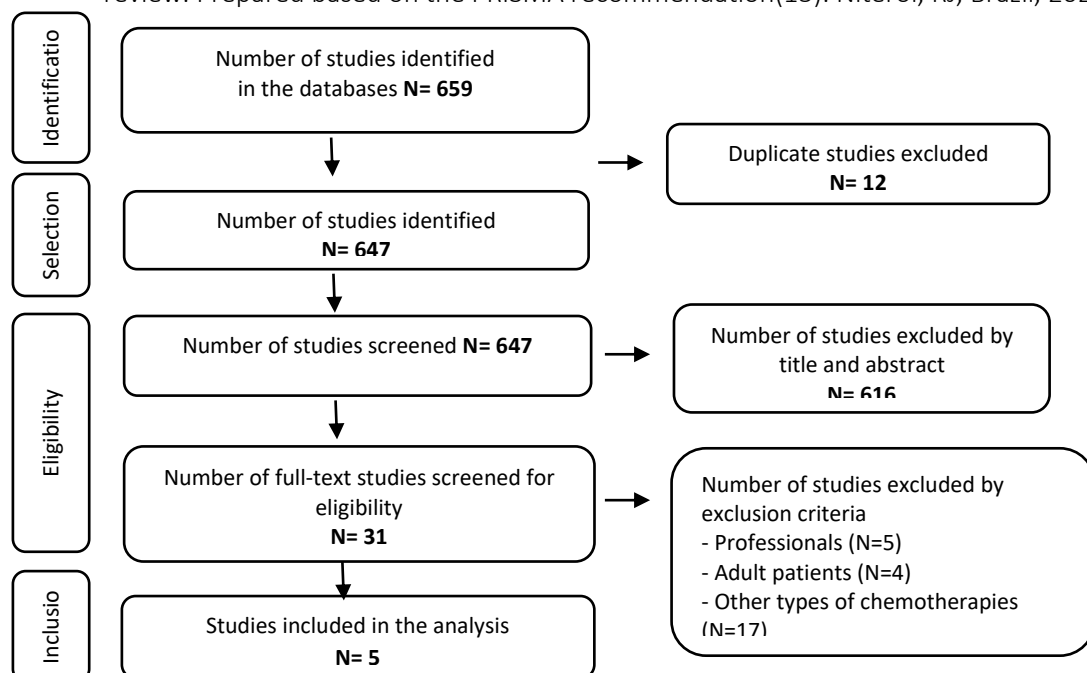
From the database search, the method of selecting and including studies followed the following steps: first, duplicate articles were removed and 12 articles were excluded from the total of 659. Then, the titles and abstracts of 647 articles were read, according to the inclusion criteria. Thereafter, 616 articles were excluded and 31 articles were read in their entirety, 26 articles

were excluded for not answering the guiding question of this review and not meeting the study objective. Therefore, the final sample was composed of five selected articles (Figure 1). The EndNote reference manager was used to exclude and organize duplicate titles and to select the studies.

To ensure the validity of the review, the selection of the studies, both the reading of the titles and abstracts and the reading in full, was carried out by two researchers independently, conflicts between these researchers were decided by a third researcher, or by consensus between those researchers.

For the selection and conduct of the studies, the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) was used in an adapted form, which aims to help authors to improve the quality of the reporting of the Systematic Review and Meta-Analysis data<sup>(15)</sup>. Figure 1 outlines the study selection process for this integrative review.

Figure 2 – Flowchart of the process of identification, selection and inclusion of studies from the integrative review. Prepared based on the PRISMA recommendation<sup>(15)</sup>. Niterói, RJ, Brazil, 2020.



Source: Research data.

To ensure the validity of the review, the studies were evaluated and classified as to their scientific rigor, for the classification of Level of Evidence (LE), using an instrument based on the Agency for Health care Research and Quality (AHRQ) categorization into seven levels of classification: level (1), systematic review or meta-analysis of controlled clinical trials; level (2), well-designed randomized controlled trial; level (3), non-randomized controlled trial; level (4), well-designed cohort or case-control studies; level (5), systematic review of qualitative and descriptive studies; level (6), descriptive or qualitative studies; and level (7), opinion of authorities or experts<sup>(16)</sup>.

For the interpretation of the results and the presentation of the review, it was decided to discuss the findings from the critical evaluation of the themes on the research question of the study. In the development of the data analysis and treatment, the authors used a form to compose a summary table with the following topics: authors, country, year of publication, type of study, level of evidence, objectives, participants, results, and educational practice used.

**RESULTS AND DISCUSSION**

The final sample comprised five publications (Chart 2), 100% from international journals. The

countries of origin of the publications that comprised the sample were: United States of America (n = 4) and United Kingdom (n = 1). It was noted that there were no national publications on this theme identified in the databases and included in the final sample of selected studies. Regarding the year of publication, it was noted that the first publication occurred in 2006 and the last publication in 2016.

As for the methodological design of the studies, descriptive studies (n = 3), prospective longitudinal study (n = 1), and non-randomized clinical trial (n = 1) were highlighted. Thus, the studies were classified according to level of evidence: three with LE 6; one with LE 4; and one with LE 3.

The clientele addressed in the studies were family members and caregivers of children and adolescents with oncohematologic pathologies being treated with oral antineoplastics in the maintenance phase of the treatment, which is characterized by daily dose-adjusted oral chemotherapy based on toxicity, monitored by blood count (1 to 2 weekly). The main oral antineoplastics were mercaptopurine, methotrexate, and thioguanine.

Figure 3 – Summary of the characteristics of the studies included in the integrative review according to authors, country, year of publication, type of study, level of evidence, objectives, participants, results and educational practice used. Niterói, RJ, Brazil, 2020.

Code	Authors/ Country/ Year	Type of study	LE	Objectives/ Participants	Results	Educational practice used
A1 <sup>(17)</sup>	Taylor JA, Winter L, Geyer LJ, Hawkins DS  USA  2006	Descriptive study	06	To assess the frequency of errors in treatment with orally administered antineoplastic drugs in children with ALL  Parents of children with ALL (N=69)	Among the 17 medication errors, 12 were categorized as administration errors, all errors occurred in children who were in the maintenance phase of treatment. They estimated that 10% to 40% of children with cancer did not receive all the prescribed doses of oral antineoplastic drugs due to lack of compliance.  With clinical consultations, the use of systematic instructions on proper administration and the use of calendars (indicating the specific drug and dose to be administered) have reduced errors in the administration of oral antineoplastic drugs.	Clinical consultation + calendar
A2 <sup>(18)</sup>	Christiansen N, Taylor KM, Duggan C  United Kingdom  2008	Descriptive study	06	Identify problems, perceptions, and information needs of parents and caregivers regarding oral antineoplastic  Parents of children with ALL (N=55)	Family members found it difficult to understand how to administer the oral antineoplastic at the beginning of therapy and that misunderstandings and errors occurred, they reported not caring about safe handling of the medications. Providing information during consultations was identified as an important factor in promoting self-care skills. Reminder letters and tailored trainings were developed for family members who were ignorant of safe handling.	Clinical consultation + reminder letters + adapted trainings for family members / caregivers
A3 <sup>(19)</sup>	Simchowit B, Shiman L, Spencer J, Brouillard D, Gross A, Connor M et al  USA  2010	Descriptive study	06	Identify vulnerabilities and opportunities for improvement in the process of oral antineoplastic use  Caregivers of children who administered the oral antineoplastic drugs (N=15)	To improve the safety of oral antineoplastic drugs, in the group dynamics the family members/caregivers suggested improving communication in the first meeting of the prescription or before hospital discharge, more frequent contact between scheduled appointments, such as telephone contact or electronic communication. They suggested the creation or availability of a professional "adverse effects specialist" to educate and guide family members about possible reactions and interactions, adverse effects, and safe handling.	Group orientation with dynamics

(continue)



Code	Authors/ Country/ Year	Type of study	LE	Objectives/ Participants	Results	Educational practice used
A4 <sup>(20)</sup>	Phillips B, Richards M, Boys R, Hodgkin M, Kinsey S  USA  2011	Prospective longitudinal study	04	Assessing parent safety and satisfaction with the home maintenance program  Parents of children with ALL (N=50)	They identified that to maintain good levels of adherence to oral antineoplastics, parents needed to be reminded of the importance of treatment, and furthermore, that counting unused medications through a tablet audit system is one method of identifying non-adherence to therapy. Demonstrated that maintaining a service to monitor and modify doses of oral antineoplastics is more convenient and preferred by family members/caregivers.	Home Maintenance Program + Tablet Audit System + Reminder Letters
A5 <sup>(21)</sup>	Zimmer J, Niemann D, Seltmann K, Fischer L, Christiansen H, Frontini R et al  USA  2016	Non- Randomized Clinical Trial	03	To identify the knowledge deficit of parents in the management of oral antineoplastic agents and evaluate two intervention strategies: manual and pharmaceutical counseling.  Parents involved in the management of oral antineoplastic agents (N=64)	The study identified a high rate of parents with knowledge deficits about the safe handling and administration of oral antineoplastic drugs. It concluded that they needed guidance strategies, and also that the pharmaceutical counseling intervention substantially reduced the knowledge deficits to 8%. At the end of the study, all participants had very good or good knowledge about the management of oral antineoplastics.	Pharmaceutical counseling + manual approach

USA - United States of America.

Source: Research data.

The evidence found in the publications was grouped according to the type of health educational practice found: Clinical consultation, Group orientations with dynamics, Home maintenance program and Production of printed educational materials.

#### Clinical consultation

In the clinical consultation performed in study A1, calendars indicating the specific drug and dose to be administered or pill boxes with the exact drugs to be administered were used to reduce administration errors<sup>(17)</sup>.

Study A2 identified, during consultations, what the information needs of parents and caregivers were regarding oral antineoplastics. Subsequently, letters were prepared with charts provided by the hospital to remind them of medication schedules, they also conducted training sessions tailored to the needs of each family member<sup>(18)</sup>.

Study A5 used two educational practices, among them pharmaceutical counseling. The consultation was performed by an experienced pharmacist who explained and oriented the families of children and adolescents on oral antineoplastic therapy, regarding the risks and safe management of antineoplastic drugs<sup>(21)</sup>.

#### Group orientation with dynamics

In study A3, they used the educational practice of group guidance with dynamics with family members of children and adolescents in treatment with oral antineoplastic drugs. This approach made it possible to understand how caregivers managed oral antineoplastic drugs and to know their experiences and main doubts about

their management. At the end of the dynamics, the orientations and training covered all the stages of the process of using these drugs, focused on the doubts and vulnerabilities reported by the family members of children and adolescents in treatment with oral antineoplastic drugs<sup>(19)</sup>.

#### Home Maintenance Program

In study A4, a home maintenance program was used as a health education practice with family members to improve adherence to treatment with oral antineoplastic drugs. To monitor and modify the dose of oral antineoplastic drugs, an audit system via tablet was used, containing the dispensing of the medication and its subsequent counting, to minimize the disproportion between the tablets returned and the prescriptions. Through this system, families who were not adhering to treatment were identified. The educational interventions included reminders about the importance of taking the oral antineoplastic, emphasis on the return of unused medications for safety reasons, clarification about the adverse effects of treatment, and letters reinforcing these messages to all caregivers<sup>(20)</sup>.

#### Production of printed educational materials

The studies A1, A2, and A4, in addition to consultations, also used printed educational materials as a health education strategy. In studies A2 and A4, the team delivered to family members reminder letters with the schedules of oral antineoplastic drugs<sup>(18,20)</sup>. Study A1 used a schedule indicating the specific drug with the dose to be administered<sup>(17)</sup>. Study A5 also used a 60-page manual for caregivers of children and adolescents being treated with oral antineoplastic drugs, in

which the risks and safe management of the drugs were explained. The manual was written in simple language, and the explanations were illustrated with pictures<sup>(21)</sup>.

The results found corroborate that health education presents itself as an important intervention strategy, whose premises point to the knowledge of family/caregivers and patients, target of the educational action, and their learning demands for the care of children and adolescents under treatment with oral antineoplastic drugs. For this, the health team must be instrumentalized, sensitized and mobilized, with the intention of leading them to autonomy in care through a dialogical and transformative health education<sup>(22)</sup>.

The responsibility for ensuring that family members are adequately prepared, informed, and supported in this oral treatment lies with the multidisciplinary team. COFEN Resolution No. 0569/2018<sup>(23)</sup>, which regulates the role of nurses in antineoplastic chemotherapy, states that it is the duty of this professional to "prepare nursing therapeutic protocols in the prevention, treatment, and minimization of adverse effects in clients undergoing antineoplastic treatment; formulate and implement educational manuals for patients and families, adapting them to their social reality".

Through the inclusion of the family in care, it is up to the nurse to build skills for health education practice, requiring guidelines that can be understood through accessible language and participatory methodology. These guidelines need to consist of drug demands, adverse effects of treatment with oral antineoplastic drugs, safe handling, storage, and disposal, and clarifications about the importance of therapy<sup>(24)</sup>.

The clinical consultations used in studies A1, A2 and A5 in the chemotherapy outpatient clinic or at home are essential to conduct care and treatment, because they allow a good bond of trust with the family, children and adolescents undergoing chemotherapy treatment with oral antineoplastic drugs. One of the functions of nurses in oncology is to act as educators to continue the care provided at home with quality and safety, helping to face the problems<sup>(25)</sup>.

The care and nursing consultations in pediatric oncology should be expanded and its actions should not be limited to technical procedures, but should extend beyond this: considering the emotional, cognitive and intuitive aspects so that the family and the child and adolescent develop skills to deal with the adversities imposed by the treatment. The difficulties pointed out by the family members, during the consultation, reveal the need for a differentiated service, seeking a more humanized care<sup>(25)</sup>.

Health education about cancer medications can be complex, as it may require education about medications used to prevent and treat treatment-related adverse effects, such as antiemetics, antihistamines, corticosteroids, and analgesics. Many of these medications are high risk and require close monitoring by the family/caregiver and the healthcare team. The nurse during the nursing consultation can guide patients/family/caregivers

about the specific care with oral antineoplastic drugs, address important issues about feeding and hygiene, the adverse effects of therapy, the risk factors that can lead to the occurrence of febrile neutropenia, infections, sepsis, and the safe handling of medication, which involves storage, handling, and disposal<sup>(26-27)</sup>.

The pharmaceutical care strategy employed in study A5, for family members/caregivers of children and adolescents under treatment with oral antineoplastic drugs is desired in the multidisciplinary team, acting with monitoring and counseling as to drug therapy. It covers health education, with pharmaceutical guidance, dispensing, pharmaco-therapeutic monitoring, systematic recording of activities, and measurement and evaluation of results. The pharmacist must interact in an active way with the patient in order to solve problems that may or may not involve the use of medication and follow up the results, so that, in this way, the dispensing of the medication to the patient is done consciously and safely. The practice of Pharmaceutical Care seeks to achieve desired and effective results of therapy in order to bring benefits and improve the quality of life of the patient, through investigation, prevention, and resolution of problems related to pharmacotherapy<sup>(28)</sup>.

Supporting the educational practice used in the study A3, group guidance with dynamics is a technique that addresses various qualitative aspects of reality, the universes of motives, beliefs, values, the interpretation of how people live. This strategy can be important to meet the bio-psychosocial needs of patients and family/caregivers, it seeks to build a space in which it is possible to make explicit the difficulties that crystallize in the course of daily life. The group dynamics, as a means for the development of educational practices, creates a favorable climate so that the orientations and trainings focus on the theme and the difficulties encountered by family members/caregivers and they can express themselves freely<sup>(29-30)</sup>.

As for home care addressed in study A4, it has been used as a means for the development of educational practices, a timely health intervention strategy for an innovative and unique care, with the potential to provide care focused on the patient's demands and needs. Health education is highlighted as an important practice of nurses in home care, which helps patients, families, and caregivers to build knowledge and skills, thus ensuring the understanding of the therapeutic plan and the continuity of treatment in the absence of the team<sup>(31)</sup>. It is a strategy that brings the family closer in such a way that it allows a more precise recognition of the needs, difficulties, characteristics and potentialities, enabling unique intervention proposals adapted to each reality<sup>(32)</sup>.

The studies A1, A2, A4 and A5 used printed educational materials as an orientation strategy. These materials, such as brochures, pamphlets, folders, booklets, and booklets, play an important role in the process of health education, and can also facilitate the learning of patients and family members in the dissemination of knowledge. The

educational materials must be easy-to-understand tools for patients and family members, with a simplified language and the use of images. All this material also contributes significantly to the work of nurses, by reiterating and supporting their assistance, in addition to standardizing the guidelines developed by the team and favoring self-care, because it works as a resource readily available for the patient and his family to consult it when faced with doubts in the development of care<sup>(33)</sup>.

The educational leaflet, in the healthcare institution, is an instructional resource used by nurses and the multidisciplinary team, being an important tool for health professionals to provide patients and their families with information in a simplified manner about the disease and treatment. At home, it is an aid tool for the family member, contributing as a guide to orientations for cases of later doubts and helping in the decision making process<sup>(33)</sup>. Easy-to-understand information, found in printed educational materials, improves the family member's knowledge of and ability to cope with the various medications that must be administered to the child or adolescent, helps to develop attitudes and skills, facilitates autonomy, and promotes adherence to treatment with oral antineoplastic drugs<sup>(34)</sup>.

In studies A2, A3, and A4, family members suggested the creation of a tool to facilitate communication with the health team. Based on this need, the relevance of new studies covering the development of technological solutions in health, aimed at improving adherence to therapy, was perceived. It is reiterated that nursing guidance is essential for a positive outcome in the treatment of pediatric cancer, by ensuring that the use of medication is done safely and effectively.

#### FINAL CONSIDERATIONS

The results of this integrative review demonstrate that the educational practices used to enable the orientation of family members/caregivers of children and adolescents under treatment with oral antineoplastic drugs, such as clinical consultation, group orientation with dynamics, home maintenance program, and the production of printed educational materials, provided better adherence to treatment, reduced errors in the administration of oral antineoplastic drugs, trained family members in the safe handling of chemotherapy, and instructed them about the adverse effects and complications resulting from therapy.

From the studies analyzed, it is possible to state that health education is essential for the preparation of family members of children and adolescents with special health needs, with demand for drug care at home. The health professional, especially the nursing team that works in the treatment with oral antineoplastic drugs, has as attributions to promote the training and the necessary orientations that promote the integral and resolute care through informative, instrumental and emotional help.

A limitation of this article was the scarcity of scientific productions with the theme, orientation and creation of strategies that aim to guide the family member regarding the safe administration of oral antineoplastic chemotherapy drugs. We also identified the absence of national studies that demonstrate the educational strategies and practices that can be applied to the Brazilian reality. Therefore, Brazil needs to advance in scientific studies for the development of health education practices for families of children and adolescents under treatment with oral antineoplastic drugs. It is also pointed out, among the possible limitations of this study, that the Portuguese, English and Spanish languages used in the search strategy may have caused the non-inclusion of some studies published in other languages.

This review contributes to nursing in the identification of the scientific production about the educational practices for family members of children and adolescents in treatment with oral antineoplastic drugs and revealed subsidies for a theoretical deepening on the theme. Thus, this study is expected to encourage the creation of new technological solutions in health in order to improve the quality of life of children and adolescents who make continuous use of drugs, favoring behavior change and adherence to treatment. Further studies are needed in order to define better health education strategies for the Brazilian reality and to investigate the long-term effects of the use of these strategies on the behavior of family members of children and adolescents undergoing treatment with oral antineoplastic drugs.

#### REFERENCES

1. Oliveira MM, Silva DRM, Ramos FR, Curado MP. Children and adolescents cancer incidence, mortality and survival a population-based study in Midwest of Brazil. *Cancer Epidemiology*. 2020;68:101795 DOI: [10.1016/j.canep.2020.101795](https://doi.org/10.1016/j.canep.2020.101795).
2. Brasil. Presidência da República. Subchefia para Assuntos Jurídicos. Lei 8.069, de 13 de julho de 1990. Dispõe sobre o Estatuto da Criança e do Adolescente e dá outras 93 providências [Internet]. Diário Oficial da República Federativa do Brasil. 1990 Jul 13 [citado: em 08 de nov. 2021]. Disponível em: <https://d.docs.live.net/5ba893c7cfb00618/Documentos/editoriais/18/Proc%204082%20ing%20Editado.docx>.
3. Instituto Nacional do Câncer José Alencar Gomes da Silva. Estimativa 2020: incidência de câncer no Brasil. Rio de Janeiro: Ministério da Saúde. 2020 [citado em: 04 de set. 2020]. Disponível em: <https://d.docs.live.net/5ba893c7cfb00618/Documentos/editoriais/18/Proc%204082%20ing%20Editado.docx>.
4. Iuchno CW, Carvalho GP. Toxicidade e efeitos adversos decorrente do tratamento quimioterápico antineoplásico em pacientes



- pediátricos: revisão integrativa. *Ciência & Saúde*. 2019; 12(1). DOI: [10.15448/1983-652X.2019.1.30329](https://doi.org/10.15448/1983-652X.2019.1.30329).
5. Mesquita JL, Arruda CAM, Macedo AF. Perfil dos pacientes em terapia antineoplásica oral em um centro oncológico. *Cadernos ESP*. 2018 [citado em: 04 de set. 2020];12(1):46-56. Disponível em: <https://d.docs.live.net/5ba893c7cfb00618/Documents/editoriais/18/Proc%204082%20ing%20Editado.docx>.
  6. Mesquita MER, Silva RP. Autocuidado e quimioterapia oral domiciliar: avaliação das práticas educativas dos enfermeiros sob a perspectiva de pacientes. *Rev Bras Cancerol*. 2016;62(3):237-45. DOI: [10.32635/2176-9745.RBC.2016v62n3.165](https://doi.org/10.32635/2176-9745.RBC.2016v62n3.165).
  7. Walsh K, Ryan J, Daraiseh N, Pai A. Errors and nonadherence in pediatric oral chemotherapy use. *Oncology*. 2016;91(4):231-6. DOI: [10.1159/000447700](https://doi.org/10.1159/000447700).
  8. Oliveira DAL, Fontes RA, Silva MB. Cuidados de enfermagem ao paciente oncológico portador de cateter totalmente implantado. *Vittalle*. 2019;31(1):52-60. DOI: [10.14295/vittalle.v31i1.8684](https://doi.org/10.14295/vittalle.v31i1.8684).
  9. Rosenberg SM, Petrie KJ, Stanton AL, Ngo L, Finnerty E, Partridge AH. Interventions to enhance adherence to oral antineoplastic agents: a scoping review. *J Natl Cancer Inst*. 2020;112(5):443-65. DOI: [10.1093/jnci/djz244](https://doi.org/10.1093/jnci/djz244).
  10. Tossin BR, Souto VT, Terra MG, Siqueira DF, Mello AL, Silva AA. Educational practices and self-care: evidence in scientific production of nursing. *REME Rev Min Enferm*. 2016;20:e940. DOI: [10.5935/1415-2762.2016001](https://doi.org/10.5935/1415-2762.2016001).
  11. Silva LCA, Signor AC, Pilati ACL, Dalfollo BR, Oliveira DR. Educational approach to cancer patients: strategies for guidance on chemotherapy treatment. *Rev Bras Cancerol*. 2019;65(1):e06305. DOI: [10.32635/2176-9745.RBC.2019v65n1.305](https://doi.org/10.32635/2176-9745.RBC.2019v65n1.305).
  12. Marshall VK, Cairns PL. Challenges of caregivers of cancer patients who are on oral oncolytic therapy. *Semin Oncol Nurs*. 2019;35(4):363-9. DOI: [10.1016/j.soncn.2019.06.00979](https://doi.org/10.1016/j.soncn.2019.06.00979).
  13. Lopes VJ, Shmeil MAH. Evaluation of computer-generated guidelines for companions of paediatric patients undergoing chemotherapy. *Rev Gaúcha Enferm*. 2016;37(esp):e67407. DOI: [10.1590/1983-1447.2016.esp.67407](https://doi.org/10.1590/1983-1447.2016.esp.67407).
  14. Sousa LMM, Marques JM, Firmino CF, Frade F, Valentim OS, Antunes AV. Modelos de formulação da questão de investigação na Prática Baseada na Evidência. *Revista Investigação Enfermagem*. 2018 [citado em: 04 de set. 2020];S2(23):31-9. Disponível em: <https://d.docs.live.net/5ba893c7cfb00618/Documents/editoriais/18/Proc%204082%20ing%20Editado.docx>.
  15. Galvão TF, Pansani TAS, Harrad, D. Principais itens para relatar revisões sistemáticas e meta-análises: a recomendação PRISMA. *Epidemiol Serv Saúde*. 2015;24(2):335-42. DOI: [10.5123/S1679-49742015000200017](https://doi.org/10.5123/S1679-49742015000200017).
  16. Galvão CM. Evidence hierarchies. *Acta Paul Enferm*. 2006;19(2):VI. DOI: [10.1590/S0103-21002006000200001](https://doi.org/10.1590/S0103-21002006000200001).
  17. Taylor JA, Winter L, Geyer LJ, Hawkins DS. Oral outpatient chemotherapy medication errors in children with acute lymphoblastic leukemia. *Cancer*. 2006;107(6):1400-6. DOI: [10.1002/cncr.22131](https://doi.org/10.1002/cncr.22131).
  18. Christiansen N, Taylor KM, Duggan C. Oral chemotherapy in paediatric oncology in the UK: problems, perceptions and information needs of parents. *Pharm World Sci*. 2008;30(5):550-5. DOI: [10.1007/s11096-008-9208-5](https://doi.org/10.1007/s11096-008-9208-5).
  19. Simchowit B, Shiman L, Spencer J, Brouillard D, Gross A, Connor M, et al. Perceptions and experiences of patients receiving oral chemotherapy. *Clin J Oncol Nurs*. 2010;14(4):447-53. DOI: [10.1188/10.CJON.447-453](https://doi.org/10.1188/10.CJON.447-453).
  20. Phillips B, Richards M, Boys R, Hodgkin M, Kinsey S. A home-based maintenance therapy program for acute lymphoblastic leukemia-practical and safe? *J Pediatr Hematol Oncol*. 2011;33(6):433-6. DOI: [10.1097/MPH.0b013e31820d882b](https://doi.org/10.1097/MPH.0b013e31820d882b).
  21. Zimmer J, Niemann D, Seltmann K, Fischer L, Christiansen H, Frontini R, et al. Managing of oral medicines in paediatric oncology: can a handbook and a pharmaceutical counselling intervention for patients and their parents prevent knowledge deficits? A pilot study. *Eur J Hosp Pharm*. 2016;23(2):100-5. DOI: [10.1136/ejhpharm-2015-000716](https://doi.org/10.1136/ejhpharm-2015-000716).
  22. Costa CIA, Pacheco STA, Soeiro G, Adame DG, Peres PLP, Araújo BBM. Construction and validation of educational materials for children with chronic disease: an integrative review. *Rev enferm UERJ*. 2018;26:e34208. DOI: [10.12957/reuerj.2018.34208](https://doi.org/10.12957/reuerj.2018.34208).
  23. Conselho Federal de Enfermagem. Resolução COFEN nº 569, de 19 de fevereiro de 2018. Regulamento técnico da atuação dos profissionais de enfermagem em quimioterapia antineoplásica. 2018 [citado em: 13 de set. 2020]. Disponível em: <https://d.docs.live.net/5ba893c7cfb00618/Documents/editoriais/18/Proc%204082%20ing%20Editado.docx>.
  24. Sueiro IM, Góes FGB, Silva LF, Moraes JRMM. Nursing care towards feeding children undergoing chemotherapy treatment:

Collière's contributions. Rev. Pesqui. 2019;11(n.esp):351-7. DOI: [10.9789/2175-5361.2019.v11i2.351-357](https://doi.org/10.9789/2175-5361.2019.v11i2.351-357).

Enferm. 2019;72(6):1519-25. DOI: [10.1590/0034-7167-2018-0505](https://doi.org/10.1590/0034-7167-2018-0505).

25. Rodrigues JRG, Siqueira Jr. AC, Siqueira FPC. Nursing consultation in pediatric oncology: a tool for empowering parents. Rev Pesqui 2020;12:210-20. DOI: [10.9789/2175-5361.rpcfo.v12.7569](https://doi.org/10.9789/2175-5361.rpcfo.v12.7569).
26. Lively A, Minard LV, Scott S, Deal H, Lambourne T, Giffin J. Exploring the perspectives of healthcare professionals in delivering optimal oncology medication education. PLoS ONE. 2020;15(2):e0228571. DOI: [10.1371/journal.pone.0228571.eCollection](https://doi.org/10.1371/journal.pone.0228571.eCollection).
27. Lambourne T, Minard LV, Deal H, Pitman J, Rolle M, Saulnier D, et al. Optimizing patient education of oncology medications: a patient perspective. J Cancer Educ. 2019;34(5):1024-30. DOI: [10.1007/s13187-018-1406-9](https://doi.org/10.1007/s13187-018-1406-9).
28. Pinho MS, Abreu PA, Nogueira TA. Pharmaceutical care in oncologic patients: a review integrative of the literature. Rev Bras Farm Hosp Serv Saude. 2019 [citado em: 13 de set. 2020];7(1). Disponível em: <https://d.docs.live.net/5ba893c7cfb00618/Documents/editoriais/18/Proc%204082%20ing%20Editado.docx>.
29. Kinalski DDF, Paula CC, Padoin SMM, Neves ET, Kleinubing RE, Cortes LF. Focus group on qualitative research: experience report. Rev. Bras. Enferm. 2017;70(2):424-9. DOI: [10.1590/0034-7167-2016-0091](https://doi.org/10.1590/0034-7167-2016-0091).
30. Queiroz MVO, Menezes GMD, Silva TJP, Brasil EGM, Silva RM. Grupo de gestantes adolescentes: contribuições para o cuidado no pré-natal. Rev. Gaúcha. Enferm. 2016; 37(e2016-0029). DOI: [10.1590/1983-1447.2016.esp.2016-0029](https://doi.org/10.1590/1983-1447.2016.esp.2016-0029).
31. Andrade AM, Silva KL, Seixas CT, Braga PP. Nursing practice in home care: an integrative literature review. Rev. Bras. Enferm. 2017;70(1):199-208. DOI: [10.1590/0034-7167-2016-0214](https://doi.org/10.1590/0034-7167-2016-0214).
32. Corrêa VB, Nunes MDR, Silveira ALD, Silva LF, Sá SPC, Góes FGB. Educational practices for families of children and adolescents using a permanent venous catheter. Rev. Bras. Enferm. 2020;73(Suppl 4):e20190129. DOI: [10.1590/0034-7167-2019-0129](https://doi.org/10.1590/0034-7167-2019-0129).
33. Cruz FOAM, Ferreira EB, Vasques CI, Mata LRF, Reis PED. Validation of an educative manual for patients with head and neck cancer submitted to radiation therapy. Rev. Latinoam. Enferm. 2016;24:e2706. DOI: [10.1590/1518-8345.0949.2706](https://doi.org/10.1590/1518-8345.0949.2706).
34. Perdigo MMM, Rodrigues AB, Magalhaes TL, Freitas FMC, Bravo LG, Oliveira PP. Educational technology for fatigue management related to antineoplastic chemotherapy. Rev. Bras.

#### Responsible Editors

Patrícia Pinto Braga  
Fabiana Bolela de Souza

**Note:** This article is a section of the dissertation entitled "Mobile application for the orientation of relatives of children and teenagers under oral antineoplastic chemotherapy treatment", presented to the Graduate Program in Professional Masters Degree Nursing Care at the Federal Fluminense University.

There was no funding by a development agency.

**Received in:** 04/11/2020

**Approved in:** 18/11/2021