Validation of the informative material for patients and their families undergoing chemotherapeutical treatment*

ABSTRACT
The objective of this study was to validate the content and comprehensibility of the informative material for patients and their families undergoing chemotherapy, while describing its utility as a written tool of communication between healthcare provider and health-care consumers. The informative material draws on information derived from twenty-three interviews of caretakers. The data were collected via surveys involving nine closed questions plus one open-ended question to analyze if the material’s content was self-explanatory, sufficient and clear. The analyses of the informative material was positive and the information within was considered satisfactory and explanatory to the majority of the interviewees. Some of the people interviewed contributed with suggestions, which were added to the material. The informative material will be introduced, aimed at improving the quality of nursing assistance provided to cancer patients, as it is believed that when health professionals are well oriented regarding the most adequate way to care, patients adhere to their treatment more seriously; in other words, the information makes them feel more secure and fosters collaboration, leading to successful treatment.

KEY WORDS
Neoplasms.
Child.
Caregivers.
Oncologic nursing.
Communication.
Health education.

RESUMO
O objetivo deste estudo foi a validação do conteúdo e a compreensibilidade do material informativo a pacientes em tratamento quimioterápico e aos seus familiares. Para avaliar se as informações do material informativo sobre câncer, quimioterapia, cuidados com paciente, alimentação e medicação eram suficientemente esclarecedoras e claras, foram contatados 23 cuidadores principais de crianças com câncer. Os entrevistados responderam a um questionário contendo nove questões fechadas e uma aberta. A avaliação foi positiva e as informações foram consideradas esclarecedoras pela maioria dos participantes, dos quais alguns contribuíram com sugestões, que foram acrescentadas ao material. Após completa finalização, o material servirá como apoio aos pacientes com câncer e aos familiares. O intuito do material é melhorar a qualidade de assistência de enfermagem, pois acredita-se que, quando os responsáveis estão orientados sobre a maneira mais adequada de cuidar, a adesão do paciente ao tratamento aumenta, a informação os torna mais seguros, e colabora para o sucesso do tratamento.

RESUMEN
Refiérase a la validación del contenido y a la comprensibilidad del material informativo a los pacientes en tratamiento de quimioterapia y a sus familiares. Fueron contactados 23 cuidadores que responderán a un instrumento con nueve cuestiones cerradas y una abierta para evaluar si las informaciones del material informativo sobre cáncer, quimioterapia, cuidados con el paciente, alimentación y medicación fueron esclarecedoras, suficientes y claras. La evaluación fue positiva y las informaciones fueron consideradas satisfactorias y esclarecedoras para la mayoría de las personas. Algunas hicieron sugerencias que fueron incluidas en el material. El material informativo pretende ser implantada con el objetivo de mejorar la calidad de la asistencia de enfermería, pues se cre que cuando los responsables están orientados sobre la manera más adecuada de cuidar, mejora la adhesión al tratamiento, la información los deja más seguros y colabora para el suceso del tratamiento.

DESCRITORES
Neoplasias.
Crianças.
Cuidadores.
Enfermagem oncológica.
Comunicação.
Educação em saúde.

DESCRIPTORES
Neoplasias.
Niño.
Cuidadores.
Enfermería oncológica.
Comunicación.
Educación en salud.

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INTRODUCTION

In addition to administrative and technical functions, nurses assume, given their background and professional practice, the role of educators in relation to patients, family members and community. This role is increasingly in demand due to the health care delivery model in which preventive actions are valued both in primary care as well as in the secondary and tertiary spheres. Nurses’ education favors the role of educator with patients. The fact that they spend more time with patients than the majority of other professionals allows them to carefully observe them, not only from the perspective of a pathology but as human beings in a holistic manner, especially in the case of children with cancer and their family members.

Considering communication an essential instrument for the nurses’ role of educator and for nursing care, we highlight the view of communication as a set of verbal and non-verbal signs emitted and perceived with the intention of exposing ideas and make them common in an understanding process. The messages themselves and the way exchange occurs influence the behavior of involved people for short, medium and long terms. This communication underpins nursing actions since nurses need to interact with patients when delivering care, thus, communication should be considered an interpersonal skill and competency to be acquired by health professionals regardless of their field of work.

Only through effective communication can nurses identify and meet the health needs of patients and help them to conceptualize and cope with their problems, and find alternatives to solve their problems. It is common to establish networks of exchange, visible or invisible, and solidarity among people involved in the cancer treatment context. In addition to promoting harmony in interactions with patients and family members, communication permits focusing full attention on them, using all channels and resources in a conscious manner to facilitate the establishment of interpersonal relationships.

Despite advancements in the information field, some issues related to the social representation of cancer are still posed. Even with the technological advancements in diagnosis and treatments for the most diverse types of the disease, a cancer diagnosis is still very much linked to the idea of终端ity. From this perspective, improving the quality of information provided about the subject is very important. In the case of childhood cancer, care delivery has to be mediated by a multidisciplinary team specializing in childcare with a view to minimize distress and assist patients and family members in the transposition of this representation.

During daily practice in the oncology field with children and caregivers, we perceived the potential of communicative exchanges and the need for printed material that supported the verbal information provided by healthcare professionals, especially nurses, and which could be taken home by those interested. There is a scarcity of informational material focused on this audience.

Based on this need, a printed instrument was developed by the nurse of the chemotherapy service of an oncology and pediatric hematology outpatient clinic in a city in the interior of São Paulo, Brazil. The content was organized according to recommendations in scientific literature about the subject. It was intended to be used in the guidance provided at the beginning of treatment, when caregivers are still under the impact of the cancer diagnosis: tense and emotionally shaken. There is a perception that there is a greater difficulty in efficiently processing information verbally transmitted in this initial span of time. The illustrated, printed material includes guidance and texts with simple language about cancer, chemotherapy, side effects, care delivered at home, food and medication.

Qualifying the content of informational material such as booklets, folders, etc. with patients and family members who have already experienced the subject is needed and represents an important gain for all, including for professionals who educate patients. It is an opportunity when one can evaluate what is missing or what was not understood; the gap between what is written and what is understood and how it is understood; misconceptions, taboos, difficulties in relation to the patient or family member and to the fact of being ill. It is a chance to validate provided information and the communication process so that this communicative resource is used in a dialogical way, with no fragmented messages or technicalities, or unidirectional, linear and limited information, being sensitive to otherness and extra-technical environments.

It is in this context that the nurses’ role as educators is emphasized. The final objective is collaboration leading to treatment success and helping patients to be re-integrated into their routine through actions focused on health education. Health education is understood as a process oriented and planned for the use of strategies that encourage individuals’ autonomy. It implies shared and non-directive actions, which enable a free decision-making process and the choice of alternatives in an adequate context of information, cognitive abilities and social support. This scenario encourages people to appropriate new forms of being and thinking in terms of health.

The nurses’ educational function should be increasingly influenced by social and economic dimensions, which require constant interpellation of individuals’ facts of life and approximation to social means and culture that are developed in such facts.

The proposed educational process is considered an important tool to provide information and support so that families of children with cancer understand what is happening.
to their health. Understanding the reason of actions and procedures favors treatment adherence, promotes changes in the way individuals feel, think and act in relation to their children and themselves. Thus, it represents a significant support in this moment of impact caused by the disease. It also encourages children and family members to avoid a passive role and start to interact with the team, exposing their doubts, anguish and feelings during the treatment.

Therefore, the objective of this study was to contribute to the dissemination of knowledge about the chemotherapy through an instructional resource, accessible and understandable to the users of this type of therapy with a view to improve the quality of nursing care and treatment success.

In summary, this study aims to contribute to the dissemination of knowledge about chemotherapy through a resource that is instructional, accessible and understandable to its users, promoting improved quality nursing care and treatment success.

**OBJECTIVE**

To validate the content and understanding of the written instrument *Instructional material for patients in chemotherapy treatment and their families* with the public to which it is directed.

**METHOD**

This is a cross-sectional and applied fieldwork with quantitative approach. Data collection was carried out in January and February of 2007 in a Clinical Pediatric Institute in the interior of São Paulo, Brazil after approval of the Research Ethics Committee at the Sâo Camilo University Center was obtained (Protocol 128/06).

The main caregivers of each child with cancer undergoing chemotherapy who voluntarily agreed to participate in the study and signed the free and informed consent form were included in the study. The person who accompanied the child in the consultations and at the outpatient chemotherapy was considered the main caregiver because this was the person who received all information and orientation about the procedures and treatment. All caregivers who accompanied patients in chemotherapy during the data collection period were contacted, totaling 23 caregivers. After individual guidance, participants received one booklet and were free to manipulate and read the material, which should be returned at the end of the consultation because it was in the validation process. Afterwards, they filled out the questionnaire that contained questions about the caregivers’ identification, nine closed questions and one open question for suggestions, which aimed to evaluate whether the information provided in the booklet about cancer and chemotherapy was sufficient and clear; guidance about care required on the day of the chemotherapy was clear; and whether information relating to food, medication and side effects was satisfactory. Respondents spent an average of 30 minutes to answer it and were allowed to use the booklet while answering the questionnaire. Illiterate individuals were excluded due to the study’s characteristics.

The answered instruments were analyzed and data were organized, grouped and presented through absolute numbers and percentages depicted in graphics so that the researcher would able to summarize, organize, interpret and communicate numerical information (21).

The answers to the open question were carefully read and their core meanings were identified, classified and incorporated into the booklet according to their contribution to content improvement.

**RESULTS AND ANALYSIS**

At the time of data collection, the studied facility treated about 340 children and adolescents, zero to 19 years old, with cancer and chronic hematological diseases. These patients were sent by the SUS or a specialist in onco-hematology requiring evaluation through the health services in the city or the region or health plans accepted by the outpatient clinic.

Children were treated at the day-hospital from Monday to Friday from 8am to 5pm where they underwent chemotherapy and received the entire support treatment in addition to oncology pediatrics, hematology, oncology orthopedics, dentistry, psychologist, nutrition, social service, laboratory, physiotherapy, playroom and pedagogical support. During weekends and when care was required out of office hours, patients were sent to pediatric general hospitals according to their health plans.

After their first visit to the outpatient clinic and diagnosis was confirmed, patients were individually evaluated by the multidisciplinary team according to their main needs. The nursing team intends to use the booklet, which is the object of this study, at this initial stage of the treatment.

The development of the instructional material was based on scientific literature in the specific field, professional experience, and daily observation of the informational needs of patients and family members cared for at the studied service. The booklet contains an illustrative cover and eight pages with information about cancer and chemotherapy treatment with messages for patients and family members explaining the booklet’s objectives and encouraging them to consult the multidisciplinary team in case of doubts and fears. It aims to clarify routes of chemotherapy application, duration of treatment, blood exams, and provides tips about what to do on the day of chemotherapy. Information about medication and food tips, including the various potential chemotherapy side effects and procedures caregivers must perform in case they occur, is also presented. The multidisciplinary team at the studied facility collaborated on the final version. The professionals collaborated on the text developed by the outpatient’s nurse according to their specialty and professional experience. The informational material was not used before this...
study so it would be first validated by and be tailored to the profile of the people attended by the service.

We also tried to avoid including too much information during the material’s development because it could distract attention from more relevant information. Language should be accessible to the patients’ and caregivers’ different backgrounds with a view to encourage interaction with the team during consultations without the use of technical terms.

According to the collected identification data, the studied population was classified based on educational level, age, gender and kinship to child in treatment. Correlation between answers and educational level was also investigated.

Twenty-one (91.3%) caregivers were mothers and two (8.7%) were fathers of patients, ages predominantly between 30 and 49 years. It has been observed during professional practice that those mothers who work are, most of the times, freed from their responsibilities at work and their bosses/firms allow a great flexibility of time for them to accompany their children during treatment. However, over the treatment course, they end up leaving their jobs due to the treatment’s complexity. One study with children and adolescents in chemotherapy found a similar result, indicating that mothers are those who generally become responsible for accompanying the patient and assume the routine of outpatient visits, hospitalizations, care, medication schedule and intercurrences. The more frequent presence of mothers is related to the fact that fathers keep working to maintain the household. There is also a perception that fathers, even when present, have more difficulty in dealing with feelings aroused by the situation, do not question the treatment and become absent when the children is in a severe condition.

This information should be part of nurses’ attentive observation to provide integral care, that is, ally technology with human care according to individual needs. Oncology services increasingly receive patients with a diversity of needs, which are not only restricted to access to treatment or biological issues, but are also related to needs caused by emotional, socioeconomic and cultural factors.

The participants’ educational level was also verified and is presented in Figure 1.

![Graph showing educational levels of caregivers](image)

Figure 1 - Educational level of studied caregivers - Jundiaí, SP, Brazil - 2007

We observe that the majority (20 participants) had up to high school, eight (34.7%) had not completed middle school and none of them had graduate education. This scenario reinforces the need for nurses to give prominence to their role as educators and to pay attention to the context of each family so care and guidance are appropriate and understandable.

There was an expectation at the beginning of data analysis that participants with higher levels of education would be more critical and contribute more to the material analysis, however, contrary to expectations, the participants who had not completed middle school participated more actively and made suggestions that certainly improved the booklet content.

The concept of autonomy, that is, people’s ability to decide for themselves in matters that concern themselves as individuals, as subjects capable of making personal choices and who should be treated with respect in relation to their ability of self-determination was related to schooling. The rationale is that children are under the responsibility of their caregivers, who make decisions related to their treatment. From this perspective and considering the different levels of education, nurses should provide clear information to these people, respecting the knowledge of each, offering alternative therapies and care, clarifying the risks and benefits inherent to each and making sure all information is fully understood, which can be aided by the use of instructional material, and finally, acknowledging their ultimate decision.

In relation to the questions used to evaluate the instructional material, the first question asked whether the information about cancer contained in the material was clarifying, to which 21 (91.3%) participants answered yes and two (8.7%) answered no. The latter did not supply reasons nor leave suggestions in the question opened to comments.

If, on the one hand the majority found that information about cancer was clarifying, on the other hand, we have to keep in mind that potential doubts may arise since there is considerable scientific production about the subject but very little directed to the lay public. An institutional didactic written material supports the educational practice in health and helps family members to memorize content, promoting standardization of information. It is worth mentioning that the disease carries stigma and prejudice, which involves cultural aspects and uncertainties in addition to many feelings that arise in family members in relation to the treatment and prognostic, especially when they first learn about the diagnosis and tension is high. An instructional booklet might stimulate the formation of bonds and patients’ verbalization of doubts to nurses, who consequently will have more material to plan individual care.

The communication process established in the nurses’ education aims to improve nursing practice as it creates learning opportunities and promotes, in patients and fam-
ily members, feelings of trust that make them feel satisfied and safe.

Question number two asked whether information about chemotherapy was clarifying, to which all the 23 (100%) participants also answered yes. New information is understood when it is related to the rationale, language and experience of those who receive it. In turn, this understanding favors acknowledgment of information and enables behavioral change related to health.

Caregivers need to know at least that chemotherapy is a systemic treatment that uses, jointly or in isolation, drugs that act in the cellular metabolism and usually causes undesirable side effects, despite advancements and research in the field to diminish them and can also involve painful and invasive procedures.

The importance of orienting patients concerning chemotherapy treatment, and what its routes of administration are, is due to many myths and misconceptions about the subject. When appropriate information is provided, fears that haunt people not familiar with the subject disappear. There are times that professionals provide explanations but the mother/caregiver does not fix the content due to the way the content is explained, or due to professional language, especially in the case of physicians who sometimes do not manage to achieve the objective of orientation. When caregivers do not understand information they start to fantasize. For this reason, the positive response of the participants reinforces the intention to implement the instructional material.

Question three asked whether the information contained in the instructional material was sufficient. Nineteen (82.6%) out of 23 participants answered yes and four (17.4%) answered no. Among those who answered no, one did not leave specific suggestions about this topic. Among those who made suggestions in the open question (last question), one asked to stress the disease severity because many people are not aware of its severity, of the risk of death or sequelae patients might be exposed to if treatment is not correctly followed. The other two suggested the addition of information about the different types of cancer, which were considered relevant and added to the booklet’s content.

The answers to this question encourage the use of this kind of material, which encourages and standardizes orientation related to health care in oncology. It can help individuals to better understand the health-disease process and seek recovery, since lack of information can hinder the care provided by family members. When information is not provided or is inappropriately provided, it can severely affect the child’s health and make parents become anxious and fearful for the future.

The fourth question asked whether information about chemotherapy was sufficient. All the 23 (100%) participants answered yes. It is important that family members and patients feel they are sufficiently clear concerning this therapy because despite all the advancements achieved with chemotherapeutic drugs, side effects, both physical and emotional, such as those related to decreased self-esteem, are still common.

The scarcity of physical, human, structural and material resources in the majority of health services including oncology is noteworthy. This need threatens the educational practice, which consequently becomes monotonous, repetitive and discouraging for both professionals and patients.

Printed instructional material favors the interactive process and dialog between nurses and patients or family members, providing a differentiated care that includes the emotional aspect in addition to the physical one, valuing care humanization, seeking to establish a connection between knowledge and affection, and establishing bonds among people.

Question five verified whether orientation concerning care required on the day of chemotherapy contained in the booklet was clear. All the 23 (100%) participants answered yes. It is extremely important that caregivers are informed about the care that should be provided to patients. Due to the current trend of deinstitutionalization, chemotherapy is performed in outpatient services and consequent side effects occur at home and it is the parents’ role to perform complex care. Parents feel more secure when communication is accessible and enables them to feel capable to participate in the child’s care together with the health team; they feel they are helping their child better. Educating for self-care is essential so that continuity of care at home as well as quality of treatment and patients’ quality of life are ensured, despite all changes that a cancer treatment might cause in the families’ routine. Emphasis on self-care implies individuals are active in the decision-making process to identify needs, the nature and actions that have to be developed in health care.

Question six asked whether information contained in the material about medication was sufficient and all the 23 (100%) agreed it was sufficient. Question seven also asked about information on medication. It asked participants to evaluate whether the orientation for medication was excellent, good, regular or poor. Sixteen (69.6%) out of 23 participants answered that the provided information was excellent and seven (30.4%) reported it was good. We believe that the results for this question were influenced by the work developed by the pharmaceutical sector. All medications are identified with a colored label and they provide a sheet that contains the color of the label related to that medication, name of the medication, prescribed dose, and days and times they have to be administered to patients, which the caregiver marks with a x right after its administration. This action avoids forgetfulness, reinforces the correct administration of medication and permits a closer and continuous follow-up by professionals. The team has to be connected and available to caregivers because the relation-
ship between the team, child and family members favors awareness of the extension and severity of the disease, treatment adherence and trust between all those involved in the process[13].

Question eight asked whether orientation concerning food tips was satisfactory. Twenty-two (95.7%) out of 23 answered yes and only one (4.3%) answered no, though this participant offered no suggestions. A good nutritional condition offers the substrates necessary for the recovery process. It is important that family members know that there are important food restrictions aimed to prevent infections that can be acquired by the ingestion of inadequately prepared food[16].

The antineoplastic treatment, due to the higher susceptibility of the immune system and organic debility associated with the drugs’ toxicity, undesirable side effects and other therapeutic complications, requires an intensive treatment of support, which includes among others, nutritional support that also takes into account the metabolic needs for the child’s growth and development[17]. Caregivers have to be aware of the child’s vulnerability and know how to identify alterations in the child’s feeding patterns and the information contained in the booklet about food; nutrition can help them in this task.

In the ninth question, information about the chemotherapy side effects was evaluated in topics (alopecia, skin abnormalities, nausea and vomiting, mouth alterations, fever, diarrhea, constipation, weight loss, sexual alterations, weakness and dizziness). These were classified as excellent, good, regular and poor. We observed that some participants did not understand that they should evaluate the information contained in the instructional material and not the side effects experienced by patients. When the lack of understanding of some participants about what they should evaluate was perceived, the researcher reinforced orientation to clarify the misunderstanding.

The evaluation of information about the side effects was considered excellent and good for the majority. Chemotherapy is a systemic treatment and has no specificities, that is, it does not selectively and exclusively destroy tumor cells. It also destroys healthy cells and for this reason side effects are frequent and can affect the child’s physical and emotional systems[13,18]. These factors greatly affect the routine of pediatric patients and of their families and concern with the risk of worsening the patient’s clinical condition is even greater in the occurrence of the treatment side effects.

Fatigue and weakness seem to be the most frequent side effects, which invariably affect mood and general emotional state.

Fatigue and weakness seem to be the most frequent side effects, which invariably affect mood and general emotional state. Children have their freedom restricted because many times they are not allowed to play so as to get dirty, ride bicycles, go to public and/or poorly ventilated places, go to parties or any other place or perform tasks that pose risks to them[13,15]. Depending on the severity of symptoms, physical and emotional stresses increase, intensifying changes in the routine of patients. However, the family needs to be well informed and try to keep the routine they kept prior to the diagnosis and treatment so that the child does not feel incapable, powerless and dependent. The family should try to keep the continuity of studies and encourage the child’s development process[13].

The last question was the open question available to those who wished to make suggestions to improve the instructional material or add other comments. Some of the answers suggesting alterations or complementation of content were already noted in the analysis of previous questions. Other comments were included. Five were compliments on the material or to the professionals of the chemotherapy unit and one participant suggested that the instructional material should contain data about vaccination of children, siblings and contact with vaccinated children and this information was also added. Another suggestion was that the material should contain information about the port-a-cath, however, due to the complexity and quantity of specific information, we determined this subject deserves an exclusive booklet, possibly the theme of a project in the future.

One comment draw our attention because the participant mentioned that if she had had contact with the instructional material in the beginning of her child’s treatment, it would have been easier because there is too much new information at the start of the process, completely unknown to parents. This statement reinforces the importance of offering instructional material at the initial point of treatment, as planned.

The valorization of this type of approach was also found in another study in which participants verbalize their interest in having written material, such as a booklet, pamphlet or folder with text and figures illustrating care procedures[14]. However, it is worth highlighting that this type of material should complement verbal orientation provided by team professionals to reinforce and encourage dialog and not to replace it or simply be handed to patients. Support texts cannot fill gaps of professionals’ attention and explanation with extremely technical content that consider patients as mere depositories of information[19].

Although it was not in the study’s purview, as it is beyond the content of the printed material, the request of one mother asking to include information and orientation regarding nursing technical procedures was considered important. She wanted, in case she and her child were sent to another hospital, to be able to “supervise” the nursing team. The reason is that when children are hospitalized in non-specialized facilities, complications in the catheters due to infection or obstruction are frequent and severely affect the therapy. Once more, the importance of proper infor-
mation is evident so that patients and family members can claim their rights and actively participate in the treatment.

**FINAL CONSIDERATIONS**

We present some considerations regarding the study’s objective, which was to validate the content and understandability of the written instrument *Instructional material for patients in chemotherapy and to their family members* with its target audience.

The majority of caregivers were the children’s mothers. The analyzed answers permit stating that the evaluation was positive and the information presented in the printed material was considered satisfactory and clear and therefore, understandable for the majority of participants. The suggestions to improve the instructional material were relevant and adopted. Contrary to what was expected, the majority of the participants with the lowest level of education pointed them out.

Question three, which evaluated information about cancer contained in the instructional material, resulted in the highest level (17.4%) of answers indicating insufficient content and also generated the largest number of suggestions to improve content.

Due to the nature of this instructional written material, we stress the need of constant updating so that the objective of educating, instructing and providing updated information is always achieved since increasing scientific technological development generates discoveries and new forms of treatment.

This study permitted inferring that this material can facilitate the actions of nurses, who seek to include family members in this new context, the disease, in a moment they are still shaken with the diagnosis. The deinstitutionalization enabled by the treatment performed in outpatient clinics and in day-hospitals requires family members to know how to deal with the treatment’s side effects and that is why education on self-care is so important. It aims to ensure the continuity of care at home and the quality of treatment at the same time it favors the creation of bonds.

We stress that there was not the pretension to exhaust the approached subject, given its complexity, but rather to collaborate with the proposal of an instrument that supported the work of nurses in oncology.

The evaluation and validation of the instructional material were very important for it to be implemented in the service, supporting the care delivered by the interdisciplinary team and highlighting the relevant role of nurses as educators. The valuable suggestions provided by the caregivers reinforce the importance of effective communication in the search for improved quality of care and consequent contribution to the success of the chemotherapy treatment. When caregivers are informed about the most adequate care, treatment adherence improves and information makes them feel more secure, which promotes treatment success.

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