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Construction of pain-related educational material for people with cancer

Construção de material educativo relacionado a dor para pessoas com câncer

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ABSTRACT

BACKGROUND AND OBJECTIVES: The incorporation of pain as the fifth vital sign represents a significant advance in the care of people with cancer, as it is widely recognized as an indicator of quality of life. Given this, it is important to adopt strategies that minimize pain, which may include complementary therapies, and when necessary, the association with pharmacological interventions. Therefore, this study aimed to build the educational material for people with cancer about strategies to minimize pain resulting from cancer and/or its treatment.

METHODS: Methodological study for the construction of educational material, in the format of a folder, based on the real needs of people with cancer, a scoping review on guidelines for minimizing pain, health literacy and guiding principles for the development of educational materials.

RESULTS: The educational material was constructed based on seven themes that refer to guidelines for reducing pain: spirituality and religiosity, physical exercises, educational practices, manual therapies, pharmacological treatment, Integrative and complementary health practices (ICHPs), therapeutic communication and monitoring family. The aim is to improve pain and intervene considerably in the quality of life of the person with cancer.

CONCLUSION: The construction of the educational material is aimed at people with cancer, their families and caregivers, and summarizes guidelines that contribute to the reduction of pain resulting from cancer and/or its treatment, improving the quality of life of these people and improving nursing care.

KEYWORDS: Cancer, Cancer pain, Nursing, Nursing care.

RESUMO

JUSTIFICATIVA E OBJETIVOS: A incorporação da dor como o quinto sinal vital representa um avanço significativo na assistência às pessoas com câncer, visto que é amplamente reconhecido como um indicador de qualidade de vida. Diante disso, torna-se importante a adoção de estratégias que minimizem a dor, o que pode incluir terapias complementares, e quando necessária, a associação com intervenções farmacológicas. Portanto, este estudo teve como objetivo construir o material educativo para pessoas com câncer sobre estratégias para minimizar a dor decorrente do câncer e/ou do seu tratamento.

MÉTODOS: Estudo metodológico para a construção de um material educativo, no formato de *folder*, fundamentado nas necessidades reais de pessoas com câncer, com base na revisão de escopo, para as orientações de estratégias para minimizar a dor, literatura em saúde e nos princípios norteadores para a elaboração de materiais educativos.

RESULTADOS: O material educativo foi construído a partir dos sete temas que remetem às orientações para a redução da dor: espiritualidade e religiosidade, exercícios físicos, práticas educativas, terapias manuais, tratamento farmacológico, Práticas Integrativas e Complementares (PICS), comunicação terapêutica e acompanhamento familiar. O objetivo é alcançar a melhora da dor e intervir consideravelmente na qualidade de vida da pessoa com câncer.

CONCLUSÃO: A construção do material educativo destina-se às pessoas com câncer, familiares e cuidadores, e sintetizam orientações que contribuem para reduzir a dor decorrente do câncer e/ou do seu tratamento com o intuito de melhorar a qualidade de vida dessas pessoas e aprimorar o cuidado de enfermagem.

DESCRITORES: Câncer, Cuidados de enfermagem, Dor do câncer, Enfermagem.

HIGHLIGHTS

- · Pain was the priority among the physical and daily living needs of people with cancer
- Spirituality, physical exercise, strategies for self-management of pain, manual therapies, integrative and complementary
 practices, therapeutic communication and family support and pharmacological treatment are all strategies for
 minimizing pain
- Nurses play a key role in care for people with pain related to cancer and/or its treatment, not just physical pain, but also existential pain

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INTRODUCTION

Cancer is classified as a chronic non-communicable disease (CNCD) characterized by the disordered growth of cells, which tend to be aggressive and uncontrollable, and can affect other areas of the body and spread between tissues or organs^{1,2}.

It is considered a serious public health problem worldwide, given its high prevalence, as well as its social and economic impact on the Brazilian health system³. In the last decade, there has been a 20% increase in the incidence of new cases. For the three-year period from 2023 to 2025, 704,000 new cases of cancer are expected, mainly in the South and Southeast regions¹. The growing incidence of cancer cases is driven by increased exposure to carcinogenic factors, an aging population and advances in diagnosis³.

Cancer treatment uses radiotherapy, chemotherapy, surgery, hormone therapy and transplants¹. Although this treatment has proven to be effective in the survival of individuals with cancer, it can have major impacts, especially on the physical, social and psychological dimensions. Symptoms such as nausea, vomiting, fatigue, weight loss or gain, diarrhea, insomnia and anxiety are considered common in the daily life of people undergoing cancer treatment. However, pain and fatigue are the most recurrent manifestations and the ones that most compromise activities of daily living⁴. Pain permeates all stages of the disease, from diagnosis to treatment, and is therefore characterized as chronic pain⁵.

Pain conceptualized as "Total Pain", a term coined by Dame Cicely Saunders, encompasses the understanding of pain in all its dimensions: physical, psychological, social and spiritual. Individuals with cancer can experience painful sensations in each of these dimensions, with varying intensities^{6,7}.

The pain that compromises the dimension of physical suffering can be seen in injuries, disease progression and responses to treatment. In the psychological sphere, mood fluctuations, apathy and depression, as well as negative feelings such as fear, insecurity about the future, suffering and compromised sexuality⁸. In the social dimension, isolation and demotivation are evident; in economic conditions, the high cost of treatment for the person and their family; and in the spiritual dimension, issues about existence and faith, beliefs, values and principles⁵. In this comprehension, there are many difficulties faced by people with cancer, from the discovery of the disease to treatment and the social support of family assistance⁹.

Based on this scenario, the present study was carried out, based on a dissertation developed in 2022, entitled "*Necessidades de suporte para o cuidado de pessoas com câncer: estudo de métodos mistos*", ("Support needs for the care of people with cancer: a mixed methods study"), carried out on individuals with cancer and health professionals from an oncology reference center in the south of Minas Gerais. Among the results, from the analysis of convergence between people with cancer and health professionals for the hierarchical determination of care support needs, it was found that, among the physical and daily living needs, pain was the priority need¹⁰.

In view of this, it is necessary to provide individuals with cancer the knowledge to ease the pain caused by cancer and/or its treatment, as it can compromise activities of daily living by causing significant changes in these people's lives. It is necessary to provide comprehensible, clear and objective guidance, taking into account sociocultural aspects, precepts that are consistent with health literature.

In the process of health education, nurses are the professionals who have direct and more prolonged contact with the sick person. This interaction makes it possible to share knowledge about care in order to meet needs, with a view to promoting, preventing and recovering health, maintaining quality of life, as well as providing support for living better with the chronic condition¹¹.

Given this context, the present study's objective was to create an educational material for people with cancer, containing strategies to minimize the pain caused by cancer and/or its treatment.

METHODS

A methodological study for the construction of an educational material. The methodological study has an approach with a configuration focused on analysis, authentication and the development of research methods and approaches¹². The study followed the stages described below: the scoping review was carried out in order to meet the general objective. The methodology used for this protocol was based on the Joanna Briggs Institute (JBI), Reviewers¹³.

In the process of designing the scoping review protocol, the acronym and mnemonic strategy PCC (Population, Concept and Context) was used, as instructed by the JBI protocol. According to the strategy, the question proposed for the review is: "What are the essential nursing guidelines that contribute to reducing pain in individuals with cancer in the outpatient scenario"? Thus, the PCC denominations were as follows: (P) population, individuals with cancer; (C) concept of interest, nursing interventions that contribute to pain reduction; and (C) context based on the outpatient setting.

The survey was carried out in electronic databases: BDENF via the *Biblioteca Virtual da Saúde* (BVS - Virtual Health Library), CINAHL (EBSCO), Web of Science (Clarivate), Latin American and Caribbean Literature in Health Sciences (LILACS) via the BVS, Pubmed/Medline. The search strategy, as shown in Table 1, was executed with the collaboration of a librarian.

For the inclusion parameters, studies were selected using the following methodologies: narrative and integrative reviews, original research/articles, systematic literature review, clinical trial, qualitative research and primary studies, in Portuguese, English and Spanish, published in the last five years. All contained information related to strategies for reducing pain in people with cancer, with the aim of minimizing physical and daily life impairment during the illness process.

The inclusion criteria were: articles with strategies developed by nurses in the outpatient setting to reduce pain, and exclusion criteria: studies developed with children and adolescents, studies restricted to care in the hospital environment, experience reports, editorials and articles that did not have free access.

As far as the gray literature is concerned, data from the websites of the National Cancer Institute (INCA), *Hospital de Amor* (Barretos - SP), A. C. Camargo Cancer Center, Albert Einstein Israeli Hospital, as well as course conclusion papers,

Table 1. Database search strategies.

Databases	Strategy
CINAHL (EBSCOhot)	("Nursing care" OR Nursing) AND (Neoplasm OR Cancer) AND ("Cancer Pain" OR "Pain Associated with Cancer" OR "Pain Associated with Neoplasm" OR "Pain in Oncology" OR "Pain Management")
LILACS (BVS)	("Nursing Care" OR "cuidados de enfermagem" OR "atención de enfermería" OR nursing OR enfermagem OR enfermería) AND (neoplasms OR neoplasias OR neoplasias OR cancer OR câncer OR cáncer OR tumors OR tumores OR tumeurs) AND ("Cancer Pain" OR "dor do câncer" OR "dolor en cáncer" OR "Pain Associated with Cancer" OR "dor associada a câncer" OR "dolor asociado con el cáncer" OR "Pain Associated with Neoplasm" OR "dor associada a neoplasia" OR "dolor asociado con neoplasia" OR "Pain in Oncology" OR "dor em oncologia" OR "dolor en oncología" OR "Pain Management" OR "manejo da dor" OR "manejo del dolor")
Pubmed (National Library of Medicine-NIH)	("Nursing care" OR nursing) AND (neoplasms OR neoplasm OR cancer OR tumor OR tumors) AND ("Cancer Pain" OR "Pain in Oncology" OR "Pain Management")
Web of Science (Clarivate)	("Nursing care" OR Nursing) AND (Neoplasms OR Neoplasm OR Cancer OR Tumor OR Tumors) AND ("Cancer Pain" OR "Pain Associated with Cancer" OR "Pain Associated with Neoplasm" OR "Pain in Oncology" OR "Pain Management")
BDENF (BVS)	("Nursing care" OR Nursing) AND (Neoplasms OR Neoplasm OR Cancer OR Tumor OR Tumors) AND ("Cancer Pain" OR "Pain Associated with Cancer" OR "Pain Associated with Neoplasm" OR "Pain in Oncology" OR "Pain Management")

dissertations and theses, all of which were downloaded from the Capes Portal, in order to obtain strategies for the reduction of pain in individuals with cancer.

Based on the real needs of individuals with cancer and the findings of a scoping review, an educational pamphlet was created. The purpose of this pamphlet is to ensure understanding of essential nursing guidelines that contribute to pain reduction in cancer patients.

The development of this educational pamphlet was guided by criteria related to content, language, layout, design, and illustrations. The content was based on the results of the scoping review, prioritizing guidelines demonstrated to have beneficial outcomes for pain management in people with cancer.

A clear, easy-to-understand language was adopted, with short, self-explanatory sentences, positive affirmations, avoiding scientific terms, in order to cater for socio-cultural diversity. The content was written in topics and subtopics in order to make it easier for the reader to understand the information.

The illustrations were created using an Artificial Intelligence (AI) image generator, Midjourney, known as an extension of Discord. The images were generated by feeding the software information described by the researcher, commanded by key words in English, in order to illustrate the characteristics of the images. The layout and design were built using the Adobe InDesign software to communicate the guidelines that can be used by individuals with cancer to reduce pain. As the educational material is aimed at an adult audience, a 14-point font was used for the title, which was two points larger than that used for the main text, and colors and shading variances were taken into account. The cover was designed to attract and interest the reader in the guidelines described in the folder.

For greater accessibility, a folder was created in the Google Drive cloud with the audios from the folder. This generated a QR code for visually impaired people, allowing them to access the material by pointing the smartphone camera at the page. This process redirects the patient to the content of an audiobook (Appendix A).

RESULTS

From the scoping review, 1460 articles were found. After exporting the articles to the online software Endnote Web, 373 duplicate articles were excluded, leaving a total of 1087 studies. After analysis in the Rayyan Systematic Review online software, 256 articles were duplicates, of which 132 articles were excluded and 124 resolved, that is, 955 articles remained for evaluation. Following the inclusion and exclusion criteria, 868 articles were excluded, 87 of which were selected to be read in full.

For better visibility, a flowchart with information on the articles to review the inclusion criteria was built and, at this stage, 63 articles were excluded for the following reasons: 29 did not have free access; 6 articles aimed to propose protocols; 6 articles did not explicitly present the strategy; 4 articles had uncertain and insufficient risk of bias; 3 articles the research did not show significant differences and/or no improvement in pain; 3 articles targeted children and adolescents; 2 articles did not present a specific intervention; 2 articles targeted analgesia as an intervention; 1 article targeted the burden of symptoms and did not present specific pain guidelines; 1 article did not target people with cancer; 2 articles referred more to the team than the patient; 1 article dealt with an instrument that characterized the quality of pain by patient location; 1 article referred to the high cost of equipment abroad; 1 article was a case study; 1 article was duplicated. Finally, 24 articles were included in the present study.

The search for grey literature, from websites and the Capes portal, resulted in 60 publications, of which 50 were not related to the eligibility criteria, 16 did not meet the objectives of the study; 9 were published more than 5 years ago; 8 did not focus on pain; 7 targeted children and adolescents; 4 were aimed at health professionals and/or caregivers; 2 had no published access; 2 did not target cancer patients; 1 pointed out the need to confirm the strategy in new studies, 1 addressed an analgesia technique. This resulted in a total of 10 articles.

DISCUSSION

From the data analysis, seven themes were constructed, organized by recurring subjects, which refer to the strategies proposed for reducing pain in individuals with cancer.

Spirituality and religiosity

Both spirituality and religiosity are relevant supports for human beings going through life¹⁵. Spirituality encompasses precise and optimistic psychic conceptions regarding the meaning and purpose of life, interpersonal bonds and satisfaction. Even if some people don't consider themselves to be religious, they may search for some meaning outside of themselves, looking for solutions to existential questions that may involve religious beliefs and/or practices in gods, philosophies and doctrines, the arts and family relevance, with the aim of searching for the essence and meaning of life¹⁶.

Religiosity¹⁶ is seen as a set of beliefs present in a group of people based on ceremonies and rites, proposing a relationship with God and the divine. Normally, religion designates norms that direct the behavior of the population to be associated with the conduct of that religious practice¹⁷.

Spirituality and religiosity feature significantly in the experiences of people with cancer¹⁷ because they seek support to cope with the challenges generated by the illness process¹⁵. People with spiritual well-being can show improvements in social, emotional and functional aspects¹⁸. Thus, spirituality can support and reduce the negative impact of the disease¹⁸, intervening considerably in the quality of life of people with cancer¹⁵.

Physical exercise

Physical exercise boosts endorphins, prevents joint and muscle stiffness, restores blood circulation and produces a significant improvement in strength, helping in the reduction of pain in individuals with cancer¹⁹, as well as restoring self-esteem and reducing fatigue²⁰. This shows that physical exercise can be beneficial in reducing cancer-related pain, during the progression of the disease and even after treatment²¹.

It is important to highlight the need to adapt physical exercise to the particular needs of each person in order to maximize the benefits¹⁹. Therefore, health professionals should encourage individuals with cancer to carry out physical activities and exercise as an adjunct to treatment¹.

Educational practices

Self-management of cancer pain can be achieved through a method in which people with cancer deliberate about pain

management, aiming to increase their self-efficacy by adopting pain relief strategies, with the mediation of health professionals²². In order to cancer pain self-management be effective, nurses need to be able to offer individual and longitudinal education to individuals with cancer, based on issues such as the level of pain, social circumstances, the environment in which they live and knowledge of pain treatment²². Comprehension of pain of people with cancer is necessary for proper support²³.

By appropriating themselves of knowledge, people can achieve positive results that can last for a long time, especially during treatment²⁴. The support of a qualified nurse is necessary to improve skills of people with cancer, family members and caregivers, providing an improvement in the self-management of pain²⁵.

The PRO-SELF Pain Management Program was produced in the German language and is considered to be an effective method for people with cancer, lasting between six and ten weeks²⁵. The intervention is based on three parameters: nursing coaching; encouragement to develop skills for self-management of pain and related symptoms; and the dissemination of knowledge through a detailed approach. It was implemented in order to ascertain the extent of its effectiveness in mitigating pain and related symptoms, and the results indicated a reduction in the pain intensity of people with cancer²⁶. Additionally, it is suggested that doctors use pain management diaries in the case of cancer patients, which refers to a psychoeducational intervention²⁵.

Although they showed extremely satisfactory results, no studies were found nationwide focusing on educational practices, which makes it difficult to adopt them as a pain reduction strategy. It is worth emphasizing that educational practices should provide explanations and solutions, using active listening and effective communication¹ in the search for positive advances in cancer treatment.

Manual therapies

Manual treatments, such as massage, are known to relieve cancer pain and can be essential for this porpouse²⁷. Massage has a significant effect on health as it activates blood and even lymphatic circulation, reduces edema and inflammation, increases the release of dopamine and serotonin, including lymphocytes, providing muscle relaxation and well-being for cancer patients^{24,28}. Similar effects are also produced by manual massagers²⁹ and by changing position²⁰.

It is evident that different therapeutic conditions and the type of cancer can affect the effectiveness of massage when dealing with cancer-related pain³⁰. A reference study of women with breast cancer proposes a tool called DRM Pain Relief, which provides pain relief through digital massage. It is a tool that has been tested in Indonesia, using devices such as notebooks and Android systems, which cause the sensation of receiving a frictional massage. It's considered an interesting discovery, given that manual massage has become an exhausting and even scarce process. The results show that the intervention is beneficial because it significantly reduces pain, providing comfort to people with cancer³¹. This strategy was also not included in the educational material because it requires the availability of a laptop computer and the Android

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operating system, making it difficult for people with cancer to access the intervention.

Pharmacological treatment

Pharmacological treatment using different pharmacological classes has a considerable effect on pain control. They are often combined with other analgesic drugs to achieve better therapeutic effects¹. It is the nurse's responsibility to identify and assess pain using validated scales and correlate the pain complaint with the underlying disease, in order to administer the drugs as prescribed, according to the stages of pain. The first step includes mild to moderate pain, the second severe pain, the third intense and persistent pain, and the fourth degree represents unbearable pain. The forms of treatment are: common analgesics, weak or strong opioids and even ablative surgeries that cause purposeful lesions in the nervous system and non-ablative surgeries, which implement a brain neurostimulation system or drug delivery systems in the central nervous system³².

Integrative and complementary health practices (ICHPs)

In Brazil, the legitimization and institutionalization of ICHPs began in the 1980s, especially after the creation of the Brazilian Public Health System (*Serviço Único de Saúde* - SUS)³³. Their objective is to prevent, promote and recover health, with the purpose of providing constant, humanized and comprehensive care. It should be emphasized that this care refers not only to the treatment of the illness, but to the person as a whole, taking into account the social context in which they are inserted³⁴.

Acupuncture is a non-pharmacological alternative that has a significant effect on musculoskeletal pain in general, as well as cancer pain²⁷, and is considered reliable and affordable²⁴. This therapeutic approach aimed at improving the quality of life and well-being of people with cancer should be used specifically as a complement to the clinical treatment prescribed by the doctor and not as the only method of treatment³⁵.

When combined with drugs, wrist-ankle acupuncture produces a significant improvement compared to the use of pharmacological therapy alone³⁶, as well as reducing the use of analgesics when combined with auriculotherapy²⁴, or even wrist-ankle acupuncture associated with auricular acupuncture³⁷.

Some studies have highlighted the need for more research into the effects of acupuncture, as there are contradictions between its effectiveness in treating cancer pain²⁸. A landmark study shows that one in two people suffering from cancer would be likely to use acupuncture because they are covered by insurance³⁸.

Auricular acupuncture is also seen as a method for reducing pain, helping to reduce the adverse effects caused by pharmacological therapy³⁹, and is considered a quick and easy-to-use method⁴⁰.

Acupressure comes from oriental medicine and is based on the principles of acupuncture. However, it is performed by applying hands and fingers to stimulate points on the ear to ease pain or promote the perception of relaxation⁴¹. It can be offered to people with cancer who experience pain during systemic treatment²⁷ to relieve symptoms such as fatigue⁴² and sleep disorders⁴³. Thus,

auricular point acupressure can be widely used as an alternative to reducing consumption of opioids⁴⁴, providing beneficial effects for the pain of individuals with cancer²⁴.

Another alternative method is foot reflexology, which plays an important role in relation to pain in cancer patients²⁷. It is indicated for individuals undergoing chemotherapy treatment, due to the signs and symptoms of adverse effects that are common during treatment³⁰. Its effects include reducing cancer patients' pain, fatigue symptoms and sleep disturbances. In addition, foot reflexology can also help reduce symptoms of depression⁴⁵.

Therefore, hypnosis^{46,47}; guided imagery²⁸; Reiki^{42,48}; music therapy^{47,49}; art therapy⁴⁸; yoga^{24,48}; auriculotherapy^{39,50}; meditation⁴⁷ and cognitive restructuring⁵¹ are also considered important strategies for the control and management of cancer pain, with effective repercussions on the quality of life of patients. The best integrative and complementary practices available in SUS were taken into account when preparing the educational material, as well as those which, although not available, showed positive results for pain relief.

Therapeutic communication and family support

Other non-pharmacological methods have been included in the individualized care of people with cancer, since they are showing effectiveness in relieving cancer pain, such as therapeutic communication and family accompaniment²⁰ and active listening⁵². It is necessary to provide an environment that is conducive to the practice of active listening, with the objective of exploring the concerns that have intensified the discomfort of the patient and their uncertainties⁵², as well as therapeutic communication and family/caregiver support, due to the coexistence in the daily life⁵³, because these are significant approaches that contribute to the control of cancer pain²⁰.

It is worth mentioning in this context that non-pharmacological treatment alternatives are aimed at specific care management, generating a positive impact on pain control²⁰. Nevertheless, although some studies have presented effective strategies for easing the pain of people facing cancer and its treatment, some articles were not included in the preparation of the educational material, as they did not fit in with the life context of the people for whom the folder was intended.

Strategies that depend on the use of electronic devices and specific software were not used in the preparation of the educational material. The unavailability of some articles in their entirety may also be a limitation of this study.

CONCLUSION

This study made it possible to create educational material in the form of a folder for people with cancer, their families and caregivers that summarizes guidelines for reducing pain resulting from cancer and/or its treatment, for improving the quality of life of these people and for improving nursing care.

Nurses play a key role in care for people with pain related to cancer and/or its treatment. This issue is not limited to physical

pain, but also existential pain, which is why strategies that make a body-mind connection, providing comprehensive care, have been included.

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AUTHORS' CONTRIBUTIONS

Luana Roberta Martins Milan: Data Collection, Conceptualization, Project Management, Research, Methodology, Writing - Preparation of the original, Writing - Review and Editing, Visualization

Monise Galante Paiva Gregorini: Conceptualization, Project Management, Writing - Preparation of the original, Writing - Review and Editing, Supervision, Visualization

Eliza Maria Rezende Dázio: Methodology, Writing - Preparation of the original, Writing - Review and Editing, Visualization

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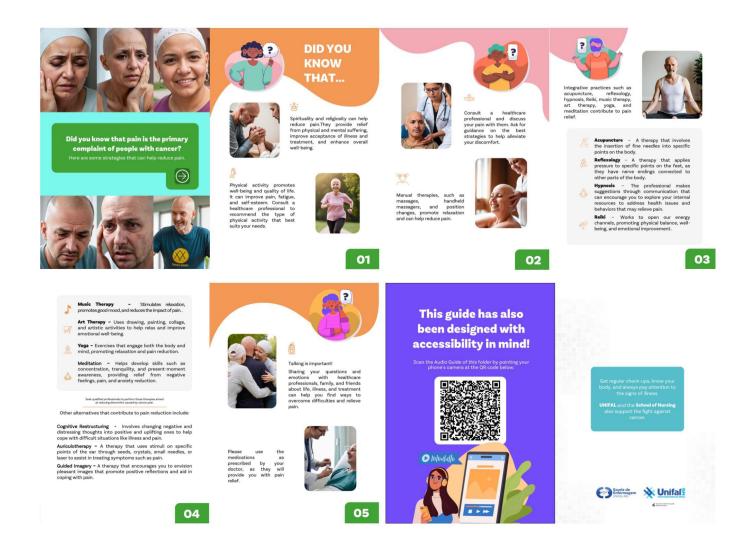
Bianca Aparecida Brito da Silva: Methodology, Writing - Preparation of the original, Writing - Review and Editing

Silvana Maria Coelho Leite Fava: Conceptualization, Project

Management, Research, Methodology, Writing - Preparation of the original, Writing - Review and Editing, Supervision, Visualization



APPENDIX A – ILLUSTRATION (FOLDER)



Maria Coelho Leite Fava, Silvana, 2024. "Replication data for: Did you know that pain is the main complaint of people with cancer? https://doi.org/10.48331/scielodata.ALT6CN, Scielo Data, draft version.