



## UNCERTAINTIES EXPERIENCED BY POST-SURGICAL PATIENTS DIAGNOSED WITH NEOPLASMS

### INCERTEZAS VIVENCIADAS POR PACIENTES PÓS-CIRÚRGICOS DIAGNOSTICADOS COM NEOPLASIAS

### INCERTIDUMBRES EXPERIMENTADAS POR PACIENTES POS-QUIRÚRGICOS DIAGNOSTICADOS CON NEOPLASIAS

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#### ABSTRACT

**Objective:** to analyze the relations between patients with neoplasm diagnosis whose treatment proposal was surgical procedure with the experience of illness uncertainty. **Method:** this is a bibliographical, descriptive study, integrative review type, from 2007 through 2017, at MEDLINE and LILACS databases, CAPES portal and Google Academics. The study included complete articles, free of charge, in English, Spanish and Portuguese. The categorical analysis raised from the identification of the meaning cores was used for the content analysis. **Results:** five categories emerged: living with uncertainty in the diagnosis and treatment of cancer; choice of surgical treatment and its consequences; application of MUIS; specialized care necessary in the management of psychosocial aspects of the person with cancer; impact of nursing interventions in reducing uncertainties. **Conclusion:** the study showed relationships between surgical oncologic patients and the experience of illness uncertainty. There is presence of uncertainty. The neglect of psychosocial aspects boosts the needs for improving communication between patient and team and coping to reduce uncertainty. Actions aimed at reducing the uncertainty affect the management of this condition in patient care, demanding a deepening of knowledge. **Descriptors:** Uncertainty; Surgery; Neoplasm; Diagnosis; Adaptation; Theory of Nursing.

#### RESUMO

**Objetivo:** analisar as relações entre pacientes diagnosticados com neoplasias que tiveram como proposta de tratamento procedimento cirúrgico com a vivência da incerteza na doença. **Método:** trata-se de estudo bibliográfico, descritivo, tipo revisão integrativa, entre 2007 a 2017, nas bases de dados MEDLINE e LILACS, no portal CAPES e Google Academics. Incluíram-se artigos completos, gratuitos, nos idiomas inglês, espanhol e português. Utilizou-se a análise categorial temática. **Resultados:** emergiram-se cinco categorias: convivendo com a incerteza no diagnóstico e no tratamento do câncer; escolha do tratamento cirúrgico e suas consequências; aplicação da MUIS; necessidade do cuidado especializado no gerenciamento dos aspectos psicossociais do indivíduo com câncer; impacto das intervenções de enfermagem na redução das incertezas. **Conclusão:** revelou-se relações entre pacientes oncológicos cirúrgicos e a vivência da incerteza na doença. Há presença da incerteza. O negligenciamento dos aspectos psicossociais impulsiona as necessidades da melhora na comunicação entre paciente e equipe e o enfrentamento para redução da incerteza. Evidenciou-se que ações voltadas à redução da incerteza influem no manejo dessa condição na assistência ao paciente, demandando aprofundamento do conhecimento. **Descritores:** Incerteza; Cirurgia; Neoplasia; Diagnóstico; Adaptação; Teoria de Enfermagem.

#### RESUMEN

**Objetivo:** analizar las relaciones entre los pacientes diagnosticados con cáncer que había como una propuesta de tratamiento procedimiento quirúrgico con la experiencia de la enfermedad la incertidumbre. **Método:** este es un estudio bibliográfico, descriptivo, examen integrador, entre 2007 y 2017, en las bases de datos MEDLINE y LILACS, el portal CAPES y Google Academics. Incluye artículos completos, de forma gratuita, en inglés, español y portugués. Se utiliza para analizar la cuestión planteada categórico desde la identificación de los núcleos de significado para el análisis de contenido. **Resultados:** emergieron cinco categorías: Viviendo con la incertidumbre en el diagnóstico y tratamiento del cáncer; la elección del tratamiento quirúrgico y sus consecuencias; la aplicación de MUIS; necesitan atención especializada en la gestión de aspectos psicossociales de la persona con cáncer; impacto de las intervenciones de enfermería en la reducción de las incertidumbres. **Conclusión:** demostró relación entre pacientes de oncología quirúrgica y la experiencia de la enfermedad la incertidumbre. Hay presencia de incertidumbre. El descuido de los aspectos psicossociales aumenta las necesidades de mejora en la comunicación entre el paciente y el personal y las estrategias para la reducción de la incertidumbre. Es evidente que las medidas destinadas a reducir la incertidumbre que afectan a la gestión de esta afección en el cuidado del paciente, exigiendo una profundización del conocimiento. **Descriptor:** Incertidumbre; Cirugía; Neoplasias; Diagnóstico; Adaptación; Teoría de Enfermería.

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**INTRODUCTION**

Neoplasms are an important public health problem. Estimates show that most of the new cases of the disease will arise in developing countries, resulting in a high rate of mortality.<sup>1</sup> Numbers show the need to work themes aimed at this population, in order to promote well-being and greater quality of life.

News as cancer diagnosis have difficult to be transmitted, once they generate different reactions in individuals that receive them. This diagnosis implies many changes, including the choice of treatment, in which surgery has a special attention. Moreover, the disease can determine the quality of life and even 'quantify' the individual's life time, which leads to the need for adaptation and search for coping.<sup>2</sup> The state of uncertainty can emerge amidst these news.

A nursing theorist, Merle Mishel, was responsible for describing the Illness Uncertainty, and published, in 1988, for the first time, the Theory of Uncertainty in Illness. The uncertainty is defined as the inability to determine the meaning of events related to the disease.<sup>3</sup> The theory highlights that, with the emergence of uncertainty in the disease context, there must be a restructuring and the search for coping mechanisms, such as the adaptation.<sup>4</sup>

The Theory of Uncertainty in Illness still reports that high levels of uncertainty associate with reduced skills, such as the processing of new information, the understanding of results and adaptation to the diagnosis of the disease.<sup>5</sup> Studies confirm that the emergence of uncertainty may lead to a feeling of lack of control over the events and negative feelings, such as: isolation, loss of identity, hopelessness and demoralization.<sup>5</sup>

Surgery is considered a usual method of treatment that produces in the individual sensations of anxiety and uncertainty. The Theory of Uncertainty in Illness highlights that, when the individual experiences the uncertainty resulting from a disease or treatment, it may result in stress. Therefore, the stress affects the mind, body and social relations. Furthermore, after the surgical procedure, the individual is likely to feel pain, momentary loss of function of the organ and some level of care dependency that affects his/her activities of daily living; adding to this, the fear of recurrence of the disease is common, as well as fear of post-surgical limitations and emotional suffering.<sup>6-7</sup>

Women undergoing surgery for treatment of neoplasms have a greater risk of existential crisis and psychological stress, especially because they do not receive quality care and a good accompaniment in the postoperative period. The care team often focuses on the disease and on later stages of treatment, thus treating conditions related to individuals' mental health as secondary. A randomized controlled clinical trial also revealed that patients who received nursing interventions such as management of symptoms, monitoring, emotional support, health education, provision of resources, references and direct nursing care, obtained as a result an important reduction of uncertainties when compared to the group that did not receive the interventions.<sup>8</sup>

**OBJECTIVE**

- To analyze relations between patients with neoplasm diagnosis whose treatment proposal was surgical procedure with the experience of illness uncertainty.

**METHOD**

The chosen method was the integrative review.<sup>9</sup> The following question guided the study: what are the relations between patients with neoplasm diagnosis who underwent a surgical procedure with the experience of illness uncertainty?

Two reviewers conducted the research from the Virtual Health Library (VHL), using the databases of Medical Literature Analysis and Retrieval System Online (MEDLINE) and Latin American Literature on Health Sciences (LILACS), in addition to *Portal de Periódicos CAPES* (CAPES Portal of Journals), which provides access to the main bases for national and international data from diverse areas, with controlled and indexed descriptors available in the Health Sciences Descriptors (DeCS) and Medical Subject Headings (MeSH): “*Uncertainty*” AND “*surgery*” AND “*neoplasm*”. In addition to the articles found by means of descriptors controlled, an article was included by the search using the uncontrolled descriptor “cancer” in Google Academics, which met the inclusion criteria and contributed to the enrichment of the worked theme.

The inclusion criteria included full-text articles, with free online version in national and international databases, in English, Spanish and Portuguese. The search included articles from 2007 through 2017, in order to obtain a better overview of the scientific production of that period. The sample

excluded dissertations, theses, monographs and articles that differed from the object of the guiding question or were in duplicity in the consulted databases.

For the content categorization, two self-prepared figures were built, containing the following information: article number, year of publication, title, design, study site, language of publication, level of evidence, objectives, results and conclusions. Both figures as the flowchart used based on the Prism strategy.<sup>10</sup> The identification of levels of evidence used the standardization provided by Oxford Center for Evidence-based Medicine.<sup>11</sup>

The thematic categorical analysis raised from the identification of the meaning cores was used for evaluation, interpretation and synthesis of studies.

RESULTS

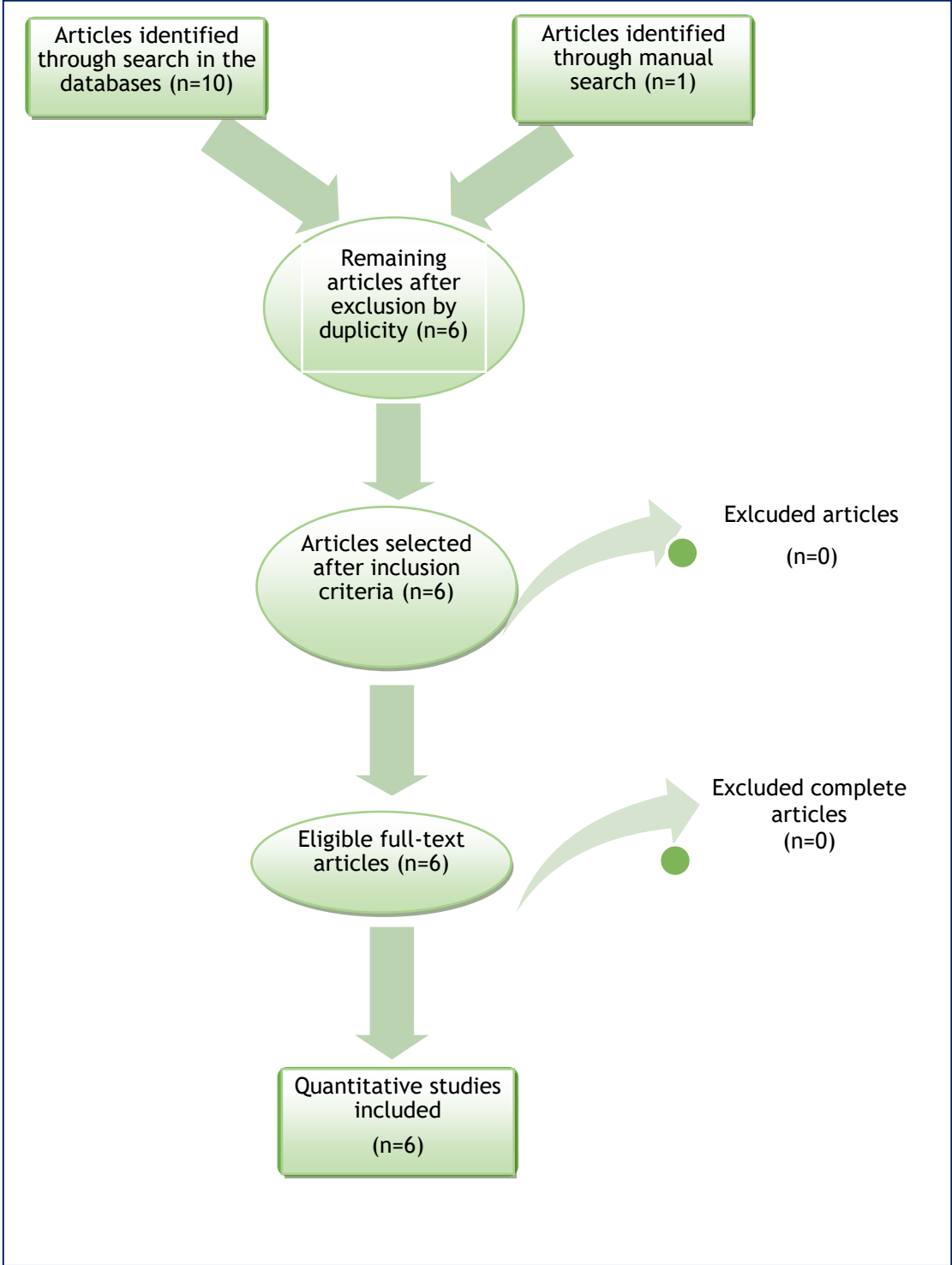


Figure 1. Flowchart of results for search and selection of articles. Adapted.<sup>10</sup> Brasília (DF), Brazil, 2018.

The search returned 10 articles in the consulted databases, of which five were excluded due to duplicity in the sample. After reading the abstracts, all five articles that remained in the revision were included once they met all inclusion criteria established, in addition to one article from the manual search.

Figure 1 shows, through a flowchart, the path travelled to choose the studies in the databases consulted.

Figure 2 shows the characteristics of the studies according to article number, year, title, design, location, language, level of evidence and database. Figure 3 summarized the theme addressed in each work, containing information on results and conclusion of the study relevant to the search.

The sociodemographic and clinical characteristics in studies were surveyed and, finally, the main categories of the studied articles were defined.

N	Year	Title	Design	Location/Language	LE	Database
1	2009	Effects of a nursing intervention on quality of life outcomes in post-surgical women with gynecological cancers <sup>8</sup>	Quantitativo	Connecticut (USA) English	1B	PubMed MEDLINE
2	2015	Illness uncertainty in breast cancer patients: validation of the 5-item short form of the Mishel Uncertainty in Illness Scale <sup>12</sup>	Quantitativo	Norway English	2C	PubMed MEDLINE
3	2009	Managing uncertainty about treatment decision making in early stage prostate cancer: a randomized clinical trial <sup>13</sup>	Quantitativo	North Carolina (USA) English	1B	PubMed MEDLINE
4	2014	Psychosocial trajectories of men monitoring prostate-specific antigen levels following surgery for prostate cancer <sup>14</sup>	Quantitativo	North Carolina (USA) English	2C	PubMed MEDLINE
5	2013	Quality of life among women after surgery for ovarian cancer <sup>15</sup>	Quantitativo	Connecticut (USA) English	1B	PubMed MEDLINE
6	2016	Relationships between gastrointestinal symptoms, uncertainty, and perceived recovery in patients with gastric cancer after gastrectomy <sup>16</sup>	Quantitativo	South Korea English	2C	PubMed MEDLINE

Subtitle: N - Article number; LE - Level of evidence.  
Figure 2. Categorization of the results. Brasília (DF), Brazil, 2018.



N	Study objectives	Results/Conclusion
1	To assess the effects of nursing interventions in women in post-surgical treatment of gynecological cancers.	The intervention group showed a significant reduction of illness uncertainty and of symptoms, demonstrating good mental and physical health.
2	To validate the “Mishel Uncertainty in Illness Scale” (SF-MUIS) and to analyze the impact of uncertainty in illness in patients with breast cancer.	The use of the Uncertainty in Illness Scale was significant. Patients reported a moderate degree of uncertainty in illness. Patients diagnosed with cancer for more than one year demonstrated a higher level of uncertainty at the expense of newly diagnosed patients.
3	To analyze the effects of managing uncertainty in illness in the decisions of treatment of prostate cancer in initial stage.	The intervention group that received actions for the management of uncertainty presented important efficacy in the management of uncertainties.
4	To describe the psychosocial trajectory of men surgically treated for prostate cancer after monitoring prostate-specific antigen (PSA) levels for 24 months post-treatment.	Three patterns of trajectory were identified: stable (patients with undetectable levels of PSA), unstable (patients with disease recurrence) and mixed trajectory (the cancer was not completely removed).
5	To describe the demographic, clinical and risk factors associated with women who underwent surgeries for malignant ovarian neoplasms.	The study demonstrated that younger, more educated and early-stage women had lower quality of life. The study also revealed that women undergoing surgeries have their psychological needs neglected at the expense of physical.
6	To examine the relationships between gastrointestinal symptoms, uncertainty in illness and perception of recovery after gastrectomy in patients with gastric cancer.	Gastrointestinal symptoms were more intense in younger women. The uncertainty index was higher in patients with low schooling and lower income. The study also found that uncertainty was the most important factor in recovery and that nurses' actions can influence crisis management, offering health education and post-operative care.

Figure 3. Synthesis of the theme addressed in the works. Brasília (DF), Brazil, 2018.

All articles addressed quantitative studies, and half of the studies designed as randomized blind clinical trials, demonstrating high levels of evidence. The randomized clinical trial is a form of experimental study, which allocates participants randomly in the intervention or control group, and this clinical design is considered the gold standard, because it minimizes the possibility of biases and errors, allowing the correlation between cause and effect.<sup>17</sup>

The population of the studies consisted of patients with the following cancers: breast, prostate, gastro intestinal tract, ovary and other gynecological cancers.<sup>8, 12-16</sup>

Regarding sociodemographic and clinical aspects of the studies, half of the population consisted of females. In general, the average age of the population ranged between 21-86 years.<sup>15</sup> Most of the population was Caucasian, with mean years of schooling from 14 through 16 years. One of the studies (n.6) demonstrated that patients with schooling corresponding to secondary education or less presented higher levels of uncertainty.<sup>16</sup> In half of the articles, the populations had higher education, the other party represented the primary schooling or less years of schooling. Populations with a lower monthly income also showed higher levels of uncertainty.<sup>16</sup>

The largest part of the population of the studies was married or in a stable relationship. The study of article n.1 revealed that the patients had more than three comorbidities<sup>8</sup> and two of the studies, n.1 and

n.6, presented, in their results, family history of cancer.<sup>8,16</sup> One of them revealed that more than 70% of the study population presented this history,<sup>16</sup> and, in another, the percentage corresponded to 77.5%.<sup>8</sup>

The article n.5 showed that patients with a family history of cancer presented lower levels of uncertainty in illness, which possibly related to the fact of having already observed the trajectory of symptoms, prognosis and treatment in their families.<sup>16</sup>

The articles also revealed that most of the population has primary cancer diagnosis; however, a significant percentage, on average, 30% of study n.1 participants, showed recurrence of cancer.<sup>8</sup> Two studies (n.3 and 4) showed that the monthly income of most patients exceeded US\$4,000.00, datum that related to the education of the population.<sup>13-14</sup> Most of the population of the studies was employed. The study n.6 mentioned that the recovery of employed patients was greater when compared to unemployed patients. This latter study attributed a possible explanation to this fact, which would be a more active social life of employed patients, which influences in the recovery.<sup>16</sup>

Another important aspect evidenced in the studies was that most of them used the Mishel Uncertainty in Illness Scale (MUIS), and one validated the American scale into the Norwegian version, corroborating the important applicability of the instrument.<sup>12</sup>

Reading and analysis of selected publications allowed identifying five themes,

namely: (1) living with uncertainty in the diagnosis and treatment of cancer; (2) choice of surgical treatment and its consequences; (3) application of MUIS (Mishel Uncertainty in Illness Scale); (4) specialized care necessary in the management of psychosocial aspects of the person with cancer; and (5) impact of nursing interventions in reducing uncertainties.

## DISCUSSION

The investigated theme did not provide a large amount of articles; however, the work resulting from the search were rich in their content, opening up great possibilities of analyses and discussions, from which five categories emerged. The discussion of the results was guided by the categories that emerged from reading the articles.

The first category, living with the uncertainty in the diagnosis and treatment of cancer, involves complex situations, cancer diagnosis and its treatment, which can generate feelings such as anxiety, fear, loneliness, lack of control of the situation and loss of self-identity, culminating in a state of uncertainty.<sup>8</sup>

Living with the uncertainty of cancer during the diagnosis and treatment can represent a huge challenge to life, due to the chronic nature of the disease.<sup>6-7, 18</sup> Studies report that patients in these conditions go through exacerbation of symptoms and fear of unknown and unpredictable situations, cause by the reduced capacity of processing information, preventing outcomes and difficulties adapting to the new conditions imposed by the disease.<sup>5</sup>

Years after finishing the treatment, a high degree of uncertainty can still be present, which imposes difficult postures for the survivors of the disease, although the triggers of uncertainties may change over time.<sup>13,19</sup> One of the studies highlights that, the more times the disease recurs, the more individuals will be able to understand their illness, influencing the reduction of uncertainty.<sup>6</sup>

According to the Theory of Uncertainty in Illness, with the advent of the neoplasm diagnosis, important concepts can be worked, such as antecedents of uncertainty, providers of structure and cognitive capacity. The antecedents of uncertainty include the framework of stimuli, which is how the individual perceives the stimuli and how he/she structures them, when he/she has no knowledge on the disease or its symptoms. The providers of structure are the suppliers of information. Cognitive capacity is the

processing of information and the ability to solve problems.<sup>4</sup> Working these concepts will allow performing the management of uncertainty in the diagnosis and during treatment.<sup>13</sup>

The category choice of surgical treatment and its consequences relates to the management of cancer and involves commonly complex and aggressive treatments. Typically, surgery is one of the main treatments of choice between the health team and patient. It involves risks, such as postoperative complications, including formation of thrombi and emboli, wound dehiscence and infection, in addition to feelings such as anxiety, sadness, depression and psychological stress; moreover, in most cases, these patients, shortly after surgery, are encouraged to begin chemotherapy.<sup>8</sup>

A clinical trial with women diagnosed with gynecological cancers showed that the studied population showed poor quality in health care and post-operative monitoring. This behavior was revealed by the neglect of the patient's psychosocial aspects, treated secondarily or even forgotten, focusing on the disease and the subsequent clinical processes.<sup>8</sup>

One of the studies proved that patients who received surgical treatment for cancer a year before reported more uncertainty than newly-operated patients.<sup>12</sup> Previous studies demonstrated that uncertainty is significantly higher in survivors of the disease after five or more years after diagnosis, which may relate to the fear of recurrence of tumor or even bad prognosis of the disease by long-term survivors.<sup>19</sup>

The surgery context can influence positively or negatively the coping. If it was an emergency or outpatient, if there was time or not to work the patient's doubts, if there is any impairment in memory or in the concentration of the patient are factors that may influence the understanding and interpretation of quality of information, therefore, the quality of information interferes directly with the consequences of the treatment.<sup>12</sup>

Most studies in the review used the Mishel Uncertainty in Illness Scale - MUIS. Regarding the category that emerged related to the implementation of MUIS, this scale is a tool of great applicability, used for measuring levels of uncertainty in illness.<sup>3</sup>

The short version of the MUIS consists of five items. Each item is classified on a scale of five points: 1 "I totally disagree", 2 "I disagree", 3 "Unknown", 4 "I agree" and 5 "I totally agree". Consequently, the degree of

uncertainty in illness can vary from five (no uncertainty in illness) to 25 (high degree of uncertainty in illness).<sup>12</sup> In addition, the scale bases on four theoretical statements: ambiguity, complexity, inconsistency and unpredictability, which represent the forms of manifestation of uncertainty.<sup>20</sup>

Another category stood out from the analysis of the articles, specialized care necessary in the management of psychosocial aspects of the person with cancer. Few studies evaluate the approach of the multiprofessional team to the psychosocial aspects of surgical recoveries. For example, social roles previously performed by patients after surgeries such as gastrectomy that implied some new adaptations were abandoned.<sup>16</sup> Not only the patients but also their families faced these challenges, whose quality of life began to change. They become less secure in the development of their activities, reduce social coexistence and go through moments of great emotional lability.<sup>21-23</sup>

The choice of the most appropriate treatment leads to the need for specialized care in the management of psychosocial aspects of individuals with cancer. The psychological maladjustment can extend due to diagnosis of the disease and the duration of treatment. In this case, it can also directly affect the quality of life. Nurse and patient should individually plan the interventions and care plan, including the individual's integral aspects. One of these studies explain that post-surgical patients need a care plan involving the monitoring of the operative wound, the use of medications, information on diet, sexuality experience, management of pain, adverse effects of chemotherapy and approaches of spiritual concerns.<sup>8</sup>

The emotional suffering of patients with neoplasms is a reality in their treatment, and a high degree of uncertainty is commonly detected; the management of this uncertainty is essential for the success of the adaptation regarding the disease.<sup>6,24</sup> The psychological well-being of the patient with cancer included controlling anxiety, attention to cognition and concentration, treatment of depression, fear management, self-concepts about the image and usefulness and motivation to cope. Aspects such as the spiritual well-being, religiosity, life purpose and spiritual needs need to be addressed with the patients.<sup>15, 25</sup>

Furthermore, in patients with neoplasms, care, in the clinical setting, usually focuses on the maintenance of numerous physical needs; however, post-surgical care included, in addition to the recovery of the body function,

the preparation for the subsequent cancer treatment. The patient's psychological needs are often considered secondary.<sup>14</sup> These aspects can make the individual vulnerable because they tend to be constantly neglected. A study with women with ovarian cancer who underwent oophorectomy showed that aspects such as loss of reproductive function, self-concept, family relations, early menopause, bad mood and physical symptoms are often considered secondary, causing major impacts in the general well-being of this population.<sup>14</sup> During hospitalization, the focus is certainly the patient's clinical stabilization. Nevertheless, in subsequent moments, such as outpatient follow-up and postoperative consultations, these psychosocial aspects treated as secondary should be inserted in the patient's treatment. Ideally, the interventions should start at the beginning of the clinical treatment.<sup>15, 24, 26</sup>

The theme of the impact of nursing interventions in reducing uncertainties was present in the discussion of all articles of this review. One of the studies on the effects of nursing interventions on the quality of life in post-surgical patients undergoing cancer treatment highlights this issue. This study highlighted that the group that received nursing interventions during six months showed a significant reduction of uncertainty in illness, when compared to the control group.<sup>8</sup> Consequently, nursing interventions used to reduce uncertainties received the attention of nursing professionals specialized in advanced oncological practice and some of the primary goals of these professionals were: assist patients in self-management of postoperative care, direct participation of treatment decisions, guidelines on the maintenance of symptoms, emotional support, organization of resources and nursing care directly offered by these professionals. The nursing interventions have shown to be effective in reducing uncertainty.<sup>14,27</sup>

Offering an individualized care plan enhances the chances of reducing uncertainty, when worked in conjunction with the nurse and the patient. This premise is explained due to the different needs of individuals. For example, the priority of care of the wound can be assigned to a specific patient, but not to all. Another example is the need to manage emotional and mental suffering of the patient in treatment, or even pain management. Therefore, only the particularization of the care plan can reveal these needs.

According to the result of one study, the low schooling influences the increase of uncertainty, explained by the difficulty of



access to information these groups have to understand the disease.<sup>18,28</sup> In contrast, approaches that assist patients in understanding and better use of information stand out in the literature as important interventions, especially in communication between doctor and patient.<sup>13, 29-30</sup>

## CONCLUSION

The study revealed the presence of illness uncertainty in cancer patients who underwent surgical treatment, evidencing the need for managing the reduction of uncertainty.

The clinical recovery of patients with cancer in the postoperative period focuses on the physical restoration, such as physiological and clinical conditions, often neglecting the psychosocial aspects of the individual and his/her emotional suffering. The review shows that healthcare providers must also focus on the care aspects, often neglected or even ignored during consultations.

The communication between patient and health team needs to be established and better worked to ensure the understanding of the messages sent and received. The patient's treatment should consider aspects such as the patient's socioeconomic profile, educational status and income.

There is also need for the nursing professional's follow-up in cancer treatment, especially in the postoperative period for reducing uncertainty. The treatment decision-making requires follow-up to reduce possibilities of regretting the choice, which depends largely on the quality of the information offered and provided.

The study shows the notorious need for deepening in this area of knowledge, since the literature had no significant amount of issues related to the topic. Nonetheless, the literature reveals the importance of increasing researches that raise the profile of patients who experience uncertainty in illness and analyze interventions to reduce these uncertainties.

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