Health advocacy in oncology nursing: an integrative literature review

Advocacia em saúde na enfermagem oncológica: revisão integrativa da literatura

Defesa de la salud en enfermería oncológica: revisión integradora de literatura

ABSTRACT

Objective: To identify the scientific production on the theme of patient advocacy by nurses in the context of oncology. Method: An integrative review with search and selection of primary studies conducted in February 2020 in four relevant databases in the health area: Lilacs, SciELO, Cochrane, and PubMed. The sample consisted of 11 studies from a universe of 395 articles. The 11 studies were grouped into two categories. Results: From the synthesis of the evidence, it was possible to elaborate the categories according to the most addressed themes: “Situations experienced by patients and nurses in which advocacy is necessary” and “Strategies that improve the exercise of advocacy”, which was subdivided into three subcategories: Self-advocacy; Support and advocacy systems for patients; Patient-Centered Communication (PCC) and Shared Decision-Making (SDM). Conclusions and implications for practice: The importance of the exercise of advocacy by nurses in oncology is evident in the studies, based on the need for communication, education, support, and recognition of the need to intervene when necessary, considering ethics as a guide to assist in decision-making, reinforcing the need for reflections on the theme by strengthening and technically basing the professional practice.

Keywords: Nursing; Medical Oncology; Patient Advocacy; Health Advocacy; Relational Autonomy.

RESUMO

Objetivo: Identificar a produção científica acerca do tema advocacia do paciente por enfermeiros no contexto da oncologia. Método: revisão integradora com busca e seleção dos estudos primários realizadas em fevereiro de 2020 em quatro bases de dados relevantes na área da saúde: Lilacs, SciELO, Cochrane e PubMed. A amostra foi composta por 11 estudos de um universo de 395 artigos. Os 11 estudos foram agrupados em duas categorias. Resultados: A partir da síntese das evidências foi possível elaborar as categorias conforme as temáticas mais abordadas, são elas: “Situações vivenciadas pelos pacientes e enfermeiros em que é necessária a advocacia” e “Estratégias que aprimoram o exercício de advocacy” que foi subdividida em três subcategorías: Self-advocacy; Sistemas de apoio e advocacy para os pacientes; Comunicação centrada no paciente (CCP) e Tomada de decisão compartilhada (TDC). Conclusões e implicações para a prática: A importância do exercício de advocacy pelos enfermeiros em oncologia é evidente nos estudos, pautando-se na necessidade da comunicação, educação, apoio e reconhecimento da necessidade para intervir quando necessário, considerando a ética como guia para auxiliar na tomada de decisões, reforçando a necessidade de reflexões sobre a temática fortalecendo e embasando tecnicamente a prática profissional.

Palavras-chave: Enfermagem; Oncologia; Defesa do Paciente; Advocacia em Saúde; Autonomia Relacional.

RESUMEN

Objetivo: Identificar la producción científica sobre el tema de la abogacía del paciente por parte de los enfermeros en el contexto de la oncología. Método: revisión integradora con busca y selección de estudios primarios realizados en febrero de 2020 en cuatro bases de datos relevantes en el campo de la salud: Lilacs, SciELO, Cochrane y PubMed. La muestra estuvo compuesta por 11 estudios de un universo de 395 artículos. Los 11 estudios se agruparon en dos categorías. Resultados: A partir de la síntesis de la evidencia, fue posible elaborar las categorías de acuerdo con los temas más abordados, que son: “Situaciones que atraviesan pacientes y enfermeros en las que es necesaria la abogacía del paciente” y “Estrategias que mejoran el ejercicio de la defensa o abogacía del paciente” que se subdividió en tres subcategorías: Autodefensa; Sistemas de apoyo y defensa de los pacientes; Comunicación centrada en el paciente (CCP) y Toma de decisiones compartidas (TDC). Conclusión e implicaciones para la práctica: La importancia del ejercicio de la defensa de los pacientes por parte de los enfermeros en oncología se evidencia en los estudios, sobre la base del fortalecimiento de la comunicación, educación, apoyo y reconocimiento de la necesidad de intervenir cuando se necesite, considerando la ética como guía para ayudar en la toma de decisiones, reforzar las reflexiones sobre el tema y afianzar los cimientos y la base técnica de la práctica profesional.

Palabras clave: Enfermería; Oncología Médica; Defesa del Paciente; Defesa de la Salud; Autonomía Relacional.
**INTRODUCTION**

The definition of *advocacy* varies depending on the context in which it is used. Traditional definitions of advocacy emerged from the legal profession in which a person's rights are defended, as well as their cause. The need to advocate for a patient is closely related to the level of autonomy the patient may have.1

Advocacy is broadly defined as a process of supporting, defending or arguing a cause, idea or policy; for example, users who need care, treatment, and other services related to their health condition can mobilize politically or take advantage of the media, requesting improvements in medical care (coverage of costs for drugs and new therapies), increased investments and improvement in communication between professionals and patients.2,3

It can be said that health advocacy is a concept based on the idea of defending against health inequities. The term is related to the construction of actions and policies that aim to reduce such inequities, characterized by living conditions related to the unequal distribution of power, income and resources among countries, social groups, and individuals.4,5

In nursing, a number of definitions may be used to describe health advocacy, ranging from acting or interceding according to the patient’s interest, protection of the patient's rights, and protection and comfort for patients unable to communicate. The multiple interpretations of health advocacy can make it difficult to analyze the role of the nurse as an advocate.1 In a study4 on the role of nurses during cancer treatment decisions, six nursing roles were described, which include the following: multidisciplinary team informant, patient educator, patient advocate, side effects management, psychological support provider, and results evaluator.

By delimiting the concept of *advocacy* to a specific context that relates public health and oncology, it can be seen that the increased cost of health care, of consumption of health products, and the increased emphasis on patient-centered care, caused a change in the dialog related to decision-making about cancer treatment among physicians and nurses.6

However, there are structural barriers related to the defense of public health that are related to the biomedical character of the hegemonic model of health care; the little discussion that uses the concepts of social determination and social inequalities to defend the right to health; the little involvement of professionals in the defense of public health; the low adherence of health professionals to politics; the low inter-sectoral involvement, and the lack of independence of some health sectors for public health advocacy.4

It is also important to consider the increase in public expenditure as a consequence of the more expensive and prolonged treatments, as well as the social security costs resulting from work leave, added to premature deaths, years of incapacity that reduces the social contribution of the individual to the development of one's own family and the nation.7

Cancer is the second leading cause of death worldwide and was responsible for approximately 9.6 million deaths in 2018. Globally, about one in six deaths is due to cancer, and by 2030 it may overcome cardiovascular disease. The total annual economic cost of cancer in 2010 was estimated at approximately US$ 1.16 trillion.8 Therefore, the economic impact of cancer is significant and increasing and, as the estimates of the disease grow, so does the need to practice public health advocacy proportionally, as it is essential to manage the impacts that the disease may cause and assist in preventing new cases.

Considering the above, the following research question arises: What is the scientific production on the theme of patient advocacy by nurses in the context of oncology, between the years 2010 and 2020? Therefore, the objective of this study was to identify what the world scientific community is discussing regarding the theme of patient advocacy in nursing, in the context of oncology for the past 10 years.

**METHOD**

This is an integrative literature review (ILR) which aims at the synthesis of knowledge, carried out in six stages.9 In the first stage, the elaboration of the review question, a theoretical study was carried out on the subject of patient advocacy in oncology nursing, which allowed for the concrete definition of the most significant variables in this approach according to the existing literature. To elaborate the guiding question of the review, the PICO strategy was used, so P (Patient) was considered for patients with cancer diagnosis or cancer survivors, I (Intervention) Advocacy, C (Control) does not apply, O (Outcome) advocacy by nurses.10

In the second stage of the search and selection of primary studies, databases were chosen according to the research question. The research was carried out in February 2020, therefore, the possibility of including articles until the present date was considered. The electronic databases of the Latin American and Caribbean Center on Health Sciences Information (BVS/BIREME)/ Lilacs, Scientific Electronic Library Online (SciELO), Cochrane, and National Library of Medicine National Library of Medicine National Institutes of Health (PubMed) were used. The third stage concerns the selection of search terms based on the words that make up the review question, identifying whether the term was presented as a descriptor or keyword. The descriptors used for data collection followed the classification of Health Sciences Descriptors (Descritores em Ciências da Saúde, DeCS), of the virtual health library, and of the Medical Subject Headings (MeSH) and were associated with the Boolean terms OR to distinguish them and AND to associate them, namely: Nursing (AND) Medical Oncology (AND) Patient Advocacy, in English. Enfermería (AND) Oncología Médica (AND) Advocacia del paciente, in Spanish. Enfermagem (AND) Oncologia (AND) Defesa do paciente, in Portuguese. In the identification of the controlled descriptors in the databases selected for conducting the review, synonyms relevant to the term of interest were also found, such as: oncology nursing OR oncology nursing/legislation and jurisprudence; patient advocacy OR advocacy OR health advocacy, also in Portuguese and Spanish. To connect the descriptors and keywords, in addition to the Boolean operators, other techniques were...
also used, including the use of parentheses to establish order in the search process and to separate the sets of terms and the quotation marks and brackets, used in cases of compound term, thus forming a search key according to Chart 1. In the fourth stage, which concerns the critical evaluation of the primary studies included in the review, the first treatment was the application of the search key in the databases. Initially, 35 publications were identified in SciELO, 177 in the Lilacs, 10 in Cochrane, and 173 publications in Pubmed. The second treatment was the application of the limits and filters that covered the 10 year interval (2010-2020) and research involving human beings, resulting in 33 in the SciELO database, 47 in Lilacs, 6 in Cochrane, and 50 in Pubmed. The 10-year time frame is justified as there were few studies published in the last five years, making the body of analysis of this integrative literature review unfeasible. The third treatment was to apply the inclusion and exclusion criteria. Studies from original research available online in full were included; published in Portuguese, English or Spanish in the aforementioned time frame. The exclusion criteria were articles published in media other than scientific journals; studies that are not available online for analysis, editorials, review articles, published in media other than scientific journals; studies that are not available online for analysis, editorials, review articles, and duplicate studies. In the fifth stage, which is the synthesis of the results of the review, these were grouped in an expository chart, the data were typed and analyzed in tables in Microsoft Word, using descriptive statistics (Chart 2) and organized according to the following variables: journal name, title, authors' names, year of publication, objectives, country, and methodology. The stage of data comparison comprised the analysis, seeking to identify themes and specificities in the selected studies, required an interpretive effort to group the data and synthesize them. The data were grouped according to similarity of theme, thus facilitating the presentation of results in categories. Finally, the sixth stage that constitutes the presentation of the data was the elaboration of the conclusions of the study, as well as the reflections that emerged during the analysis. The descriptive form was adopted for the analysis of the evidenced results, in which the synthesis of each study included in the review was presented, as well as comparisons among the researches when pertinent. This study did not need to be submitted to a Research Ethics Committee because it is an ILR and used public domain sources for its realization. Ethical care was strictly followed in the search, analysis, discussion, and presentation of results.

RESULTS

395 studies were preliminarily identified by searching the selected databases and, after selecting the filters and limits, the number was reduced to 136 studies. Subsequently, the inclusion and exclusion criteria were applied and the studies were evaluated for adherence to the theme and affinity to the research question. Thus, 47 studies were excluded because they were duplicated, 11 did not have an abstract and were not available and, finally, 67 articles did not address the theme and were also excluded. A total of 11 primary studies were obtained for analysis.

Figure 1 shows the flowchart that describes the route for the selection of articles, based on the PRISMA model.

Regarding the characterization of the primary studies that constituted the body of analysis, all were found in the Pubmed database and in Lilacs (duplicates), in the English language, with the countries of origin being the United States (n=10) and Australia (n=1). As for the year of publication, the largest number of published studies was in the years 2010 (n=3) and 2016 (n=3), followed by 2013 (n=2) and the others in the years 2011 (n=1), 2015 (n=1), and 2017 (n=1). Considering the methodological characteristics, the qualitative research with eight studies (n=8), two quantitative descriptive researches (n=2), and one quanti-qualitative study (n=1) stand out. The studies carried out with nurses totaled five (n=5), with nurses and other health professionals (n=1), and five (n=5) with patients who already had or are diagnosed with cancer. Regarding the method, three used semi-structured interviews (n=3); of these three, one also used a questionnaire and the other non-participant observation. The use stands out of the focus group (n=3), questionnaire (n=2), pre- and post- online tests (n=1), download of messages from an online community (n=1), and cognitive interview (n=1).

Chart 1. Database search strategy.

<table>
<thead>
<tr>
<th>Database</th>
<th>Search strategy</th>
<th>Studies Found</th>
<th>Limits/Filters*</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCIELO</td>
<td>(((“nursing”[MeSHTerms]) AND (((“medical oncology”[MeSHTerms]) OR “oncology nursing”[MeSHTerms]) OR (“oncology nursing/legislation and jurisprudence”[MeSHTerms]))) AND (((“patient advocacy”[MeSHTerms]) OR advocacy) OR health advocacy)</td>
<td>35</td>
<td>33</td>
</tr>
<tr>
<td>LILACS</td>
<td>Nursing AND “Medical Oncology” AND “Patient advocacy”</td>
<td>177</td>
<td>47</td>
</tr>
<tr>
<td>COCHRANE</td>
<td>Nursing AND “Medical Oncology” AND “Patient advocacy”</td>
<td>10</td>
<td>6</td>
</tr>
<tr>
<td>PUBMED</td>
<td>(((“nursing”[MeSHTerms]) AND (((“medical oncology”[MeSHTerms]) OR “oncology nursing”[MeSHTerms]) OR (“oncology nursing/legislation and jurisprudence”[MeSHTerms]))) AND (((“patient advocacy”[MeSHTerms]) OR advocacy) OR health advocacy)</td>
<td>173</td>
<td>50</td>
</tr>
</tbody>
</table>
Chart 2. Description of the primary studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Database</th>
<th>Title</th>
<th>Authors</th>
<th>Year</th>
<th>Country</th>
<th>Study objective</th>
<th>Research method</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Pubmed</td>
<td>Development of the Fertility and Cancer Project: An Internet Approach to Help Young Cancer Survivors</td>
<td>Meneses et al.¹¹</td>
<td>2010</td>
<td>USA</td>
<td>To describe the development of the “Fertility and Cancer Project”; to describe the characteristics of the FCP participants, fertility, knowledge about cancer and the use of the internet; to evaluate access to information and support from the oncology team</td>
<td>Descriptive quantitative research</td>
</tr>
<tr>
<td>2</td>
<td>Pubmed</td>
<td>Nurse Autonomy in Cancer Care</td>
<td>Gagnon et al.¹²</td>
<td>2010</td>
<td>USA</td>
<td>To explore the perception of autonomy of oncology nurses and to understand how they develop and present autonomy in their daily practice</td>
<td>Qualitative research</td>
</tr>
<tr>
<td>3</td>
<td>Pubmed</td>
<td>Scope of practice of the breast care nurse: A comparison of health professional perspectives</td>
<td>Jones et al.¹³</td>
<td>2010</td>
<td>AU</td>
<td>To identify the challenges and the role of the nurse on breast care</td>
<td>Quantitative qualitative research</td>
</tr>
<tr>
<td>4</td>
<td>Pubmed</td>
<td>Measuring Oncology Nurses’ Psychosocial Care Practices and Needs: Results of an Oncology Nursing Society Psychosocial Survey</td>
<td>Gosselin et al.¹⁴</td>
<td>2011</td>
<td>USA</td>
<td>To develop and implement a survey of the Oncology Nursing Society (ONS) members focused on their current practices and needs in relation to the provision of psychosocial care</td>
<td>Descriptive quantitative research</td>
</tr>
<tr>
<td>5</td>
<td>Pubmed</td>
<td>A Double Whammy: Health Promotion Among Cancer Survivors With Preexisting Functional Limitations</td>
<td>Volker et al.¹⁵</td>
<td>2013</td>
<td>USA</td>
<td>To explore the experience of living with a preexisting functional disability and a cancer diagnosis; to identify strategies that promote the health of the cancer survivor population</td>
<td>Descriptive qualitative research</td>
</tr>
<tr>
<td>Study</td>
<td>Database</td>
<td>Title</td>
<td>Authors</td>
<td>Year</td>
<td>Country</td>
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<tr>
<td>6</td>
<td>Pubmed</td>
<td>Ovarian Cancer Survivors’ Experiences of Self-Advocacy: A Focus Group Study</td>
<td>Hagan et al.</td>
<td>2013</td>
<td>USA</td>
<td>To explore the experiences of ovarian cancer survivors on Self-Advocacy in symptom management</td>
<td>Qualitative research</td>
</tr>
<tr>
<td>7</td>
<td>Pubmed</td>
<td>A Qualitative Analysis of “Naturalistic” Conversations in a Peer-Led Online Support Community for Lung Cancer</td>
<td>Lobchuk et al.</td>
<td>2015</td>
<td>USA</td>
<td>To describe the content of the messages in an online lung cancer support community in the United States</td>
<td>Qualitative research</td>
</tr>
<tr>
<td>8</td>
<td>Pubmed</td>
<td>Barriers and Promoters to Participation in the Era of Shared Treatment Decision-Making</td>
<td>McCarter et al.</td>
<td>2016</td>
<td>USA</td>
<td>To identify barriers and promoters for participation in cancer treatment decisions in the era of shared decision-making</td>
<td>Qualitative research</td>
</tr>
<tr>
<td>9</td>
<td>Pubmed</td>
<td>Communication During Palliative Care and End of Life</td>
<td>Montgomery et al.</td>
<td>2016</td>
<td>USA</td>
<td>To describe the common characteristics of the perceptions of communication during palliative care and end of life; to describe the perceptions of the barriers and facilitators for effective communication of nurses</td>
<td>Qualitative research</td>
</tr>
<tr>
<td>10</td>
<td>Pubmed</td>
<td>Engaging Patient Advocates and Other Stakeholders to Design Measures of Patient-Centered Communication in Cancer Care</td>
<td>Treiman et al.</td>
<td>2017</td>
<td>USA</td>
<td>To develop and test research questions to assess patients’ experiences with “Patient-Centered Communication” in cancer treatment</td>
<td>Qualitative and descriptive research</td>
</tr>
<tr>
<td>11</td>
<td>Pubmed</td>
<td>TBC update: attitudes of oncology nurses concerning pharmacogenomics</td>
<td>Dodson</td>
<td>2017</td>
<td>USA</td>
<td>To develop an interactive educational module and a pilot test of the instrument</td>
<td>Qualitative research</td>
</tr>
</tbody>
</table>
DISCUSSION

The data found in the different primary studies included in this ILR were summarized in two categories, entitled “Situations experienced by patients and nurses in which advocacy is necessary” and “Strategies that improve the practice of advocacy.” The category “Strategies that improve the practice of advocacy” was subdivided into three subcategories: Self-advocacy; Support systems and advocacy for patients; and Patient-Centered Communication (PCC) and Shared Decision Making (SDM).

Situations experienced by patients and nurses in which advocacy is necessary

This category deals with the situations and reports of patients and nurses identified in the studies in which an intervention related to health advocacy would be necessary.

A study\(^{17}\) presents as a result situations in which it was necessary for the nurses to practice advocacy or when the patients identified that they needed support; however, they did not obtain it. In the reported situations, the nurses believed that it was their responsibility to be a “lawyer” for the child and the family during palliative and end-of-life care. The nurse’s performance was closely linked with the ability to communicate and use knowledge to provide proactive guidance, solve problems with creative solutions, recognize the importance of planning advanced care to avoid crises, and respect the religious beliefs of family members, but acting as advocates for the real needs of children.

The nurses in the study pointed out that, in order to deal with the evolution of palliative care until the end of life, it was necessary to have competence in knowledge, expansion of the essence of care, and commitment to advocacy, as they often faced ethical conflicts such as the interference of religion, and when parents chose to limit the flow of information related to the stage of the disease to their child, or when children refrained from communicating concerns about the end of life to protect their parents.\(^{17}\)

Another study\(^{15}\) addresses the importance of the professionals acting as defenders and providing social support to patients diagnosed with cancer and who had a previous disabling condition. The participants described their efforts to be their own advocates and to educate their caregivers about their pre-existing conditions. Some described difficult experiences in hospitalization in which the caregivers were indifferent to their needs for self-care; others described problems with access to hospital facilities that had significant barriers for people with mobility and visual impairment. Most experienced concern about oncologists’ ability to recommend cancer treatment, taking into account the other underlying diseases and limitations.

A study\(^{2}\) prioritized analysis about putting oneself in the other’s place, because many times nurses are being asked the following by the patients, “if it were with you, what treatment would you choose?” This question portrays the patients’ high level of trust with nurses and positions these professionals to become trusted advocates for the patients, particularly when they cannot advocate for themselves.

One of the conditions for nurses to practice advocacy is described as having freedom, using knowledge to make decisions. The specialist nurses in oncology who participated in a study\(^{12}\) signaled that being up to date about the disease and treatments was a prerequisite to help the patients become more confident and comfortable during clinical decisions. They described how they used their specialized knowledge of cancer to advise the patients on coping strategies, teach self-care behaviors, and monitor responses to the treatment and nursing interventions. Still, this study reasserts the relation between professional autonomy and the defense of the patient, that is, how much the decision making of oncology nurses is directly linked to the attitudes of advocacy with oncology patients.

The advancement in cancer treatment brings some questions to the fore, such as effectiveness, cost and inequities. In the United States, approximately 25% of the patients spend most of their savings during cancer treatment. The term “financial toxicity” has been used to describe the current concern in the area of oncology.\(^{19}\) In this case, it is essential to promote awareness of this “financial toxicity”, through advocacy. Thus, the author also talks about the importance of information in advance, specifying the situation of genetic tests and communication that is easy for the patient to understand.\(^{19}\)
Strategies that improve the practice of advocacy

The term Self-advocacy was defined as a process of learning one’s own needs and priorities as an individual with cancer or survivor and negotiating with health, social support, and other survivors to meet these needs.16

A phenomenological study16 identified the main dimensions and a preliminary definition of Self-advocacy, in which nurses can recognize and support when patients seek and receive care consistent with their own needs and preferences.

Still, another study15 mentions that the concept of Self-advocacy appeared in the discussion of all the questions in the focus groups carried out. The survivors talked about trying to educate cancer care providers about their specific needs and included Self-advocacy as a health promotion strategy and as an important component of wellness programs for cancer survivors with pre-existing functional limitations. The importance was emphasized of teaching people to manage their care through Self-advocacy and education, and to find affordable health services with professionals sensitive to their needs.

Another study15 pointed out the importance of defense and social support in the context of cancer patients who had a disabling condition, as the unprivileged population and individuals with disabilities experience health disparities, being more likely than people without disabilities to suffer delays and decrease in obtaining health care, and therefore have higher cancer-related mortality rates.

Therefore, exercising advocacy for the patients is also educating them to defend themselves, and communication has a fundamental role in this process. Information exchange refers to communication in order to assess and understand the information that patients need, facilitate mutual sharing, and achieve a common understanding. Decision making refers to communication in order to understand the patients’ preferences for participation in decision making, to make them aware when there is a decision to be made, to involve them so that decisions are based on the best scientific evidence, and to reflect on their values. Fostering healing relations implies communication that generates trust, relationship, commitment, and mutual understanding about roles and responsibilities, allowing self-management of the disease (for example, controlling symptoms and side effects).18

One of the examples of Self-advocacy is portrayed in this study by women who signaled having received symptom management advice from health professionals, from advocacy organizations, from friends and from the Internet, and so they figured out how to filter and manage the information to meet their needs and goals. They also reported being proactive in guiding the health team to recognize their own priorities, beliefs and values, in order to justify their own choices regarding their treatment and care. The women often used Self-advocacy in decisions to reduce their dosage of chemotherapy or not taking medication because of unwanted side effects. Furthermore, with extended survival, it is often necessary to process the evolution of the challenges on their own, outside the traditional clinical environment.16

In turn, support and advocacy systems are online support communities and monitored forums that are part of the web or a social network in which people communicate with each other, sharing information. These communities are monitored by professionals and their peers, led by explicit rules of online behavior. Peer-led users can also assist in managing these communities. This type of support can collaborate to minimize the impact of stress on health, reevaluating what may be a threat and encouraging positive coping behaviors. Users of monitored online support communities often discuss emotions, seek and provide information about cancer (medical information, treatment, therapeutic responses), in addition to sharing the daily diagnosis and offering spiritual support, but no therapy is offered.2

A study11 involving 106 young women who survived breast cancer describes that 24% of them claim to have received enough emotional support from their oncology caregivers, and 11% have received enough information on preserving fertility. Preliminary results of the “Fertility and Cancer” project covered by this study contributed to the body of knowledge of young breast cancer survivors and their experiences in search of health information on fertility. First, young women survivors of breast cancer use the Internet to search for information on fertility and, despite having a good level of education and an above average income, many do not have immediate access to information through traditional sources, that is, with the professionals. And three quarters of the participants got to know the “Fertility and Cancer” group through other online advocacy groups and research on the Web, which suggests that young breast cancer survivors often create a network with other cancer survivors.11 In this study, it was possible to identify that the advocacy groups’ strategy was focused on the dissemination of the “Fertility and Cancer” project, reinforcing the understanding that advocacy, in this case, favors patients’ autonomy through the support process when offering welcoming and necessary information through online media.

As for the support groups, a study2 presents “The Breast Care Nurse” (BCN), which is a group of nurses who develop a work aimed at the care of patients with breast cancer. The idea was formally introduced in the health services of Australia in the late 1990s to facilitate better continuity of care and psychosocial support. The nurse’s role is to coordinate patient care, making calls to other professionals, intervening, and defending the patient when necessary. It mentioned that nurses also provided psychosocial information and support to patients’ families.

In a study14 conducted by the Oncology Nursing Society (ONS) with 401 nurses, it was found that 60% of them used support groups as tools and methods to help patients and families, as these groups offer guidance (for example, self-advocacy) and 88% considered support groups accessible and available as a psychosocial resource. In addition, 35% of the participants consider the nurse to be the professional responsible for providing psychosocial health services, surpassing the 33% who identified the social worker.

Finally, Patient-Centered Communication (PCC) comprises communication among patients and professionals and requires
Health advocacy in oncology nursing
Neves FB, Vargas MAO, Zilli F, Trentin D, Huhn A, Brehmer LCF

four fundamental attributes: consideration of the patients' needs, perspectives and individual experiences; creating opportunities for patients to participate in their care; and the physician strengthening the patient. In the context of cancer patients, PCC helps patients in many ways, such as receiving difficult news and dealing with the emotional impact of a potentially fatal disease, understanding the most complex medical information, communicating with various health professionals, dealing with uncertainty, making decisions about what is important, and adopting health-promoting behaviors.

Failures in communication and non-advocacy may cause consequences such as inadequate symptom management, decreased quality of life, medication errors, and misunderstandings about the care preferences of the patients and their families. In addition, the lack of communication about care planning may lead to aggressive and unwanted therapies for the patient.

Shared Decision Making (SDM) is a health care delivery model that postulates four fundamental principles: at least two participating physicians and the patient involved; both parties share information; both parties build consensus on preferential treatment; and an agreement is reached on the implementation of the treatment. This model is relevant in oncology because the nurses were identified as the main professionals who are sources of information, control the side effects of chemotherapy, evaluate the results of treatment, and advocate on behalf of the cancer patients. Thus, the SDM model incorporates the patient, physicians and nurses alike.

The principles of SDM require nurses to perform complex roles in cancer treatment decision making, which include the following: patient educator, informant during the exchange of information among members of the health care team and the patient, and advocacy to reach a treatment decision which is agreed among patients, physicians, nurses, and other members of the health team.

The limitations of the present study are related to the scarce number of primary studies eligible to compose the ILR; and to the survey of methodological data, since some studies did not explicitly present the description of the methodology.

FINAL CONSIDERATIONS

Considering that, although advocacy is permeated with subjectivities, it is still possible to list key elements that come to be the structuring of the defense of cancer patients/users. The indicators of the advocacy framework in the studies addressed in this ILR are related to the patient's autonomy in seeking their rights, the professional's autonomy in defending their patient, and the right to information and communication.

The issue of the ethical obligation to inform the patients must be inherent to care since it is the patients’ right to be informed about their health condition and thus promote their autonomy. Therefore, it is necessary to know how to manage dilemmas and ethical problems that may arise when information generates anxiety and stress. However, the expansion of the nurse's role in caring for cancer patients has increased autonomy with regard to the cancer treatment decision-making process, and it can result in patient satisfaction.

It was pointed out as an important factor that the findings discussed in this study are international, reinforcing not only the scarce production on the subject, but the gap that exists mainly in our country. Still, it was considered that the content of these productions and the relevance of the theme nowadays make the development of this study essential for the production of future studies that may address this theme nationally. It should also be noted that none of the studies had the purpose of analyzing Advocacy, but this theme emerged from the data as expressed by the research participants and in the concepts of the topics covered. Furthermore, it is necessary to produce studies that allow professionals to quantify and qualify how much patients/users are being defended, that is, what the results of this practice are and how the indicators are approached or carried out so that the defense occurs effectively.

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Study design and review. Data acquisition and analysis, and interpretation of the results. Content writing and/or critical review. Approval of the final version of the article. Responsibility for all aspects of the content and integrity of the published article. Franciele Budziareck das Neves.

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REFERENCES


