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Approach to sexuality in the care of cancer patients: barriers and strategies

Abordagem da sexualidade no cuidado ao paciente oncológico: barreiras e estratégias

Abordaje de la sexualidad en el cuidado del paciente oncológico: barreras y estrategias

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Abstract

Objective: To identify intervening factors in the approach to sexuality, by patients and professionals, and to describe strategies used in this approach in the care of cancer patients.

Methods: Integrative literature review, based on systematic steps, databases and/or electronic libraries: LILACS, PubMed, MEDLINE, IBECs, SciELO, UpToDate, BDeInf. Searches were carried out between December 2016 and July 2017. Inclusion criteria: studies with cancer patients aged over 18; published in the last ten years (2007-2017); available in full; written in Portuguese, Spanish, and English. Theses, essays, reviews (systematic, narrative, and integrative), opinion articles and editorials were excluded.

Results: Eighteen articles were included, six of which were related to intervening factors, and 12 articles related to strategies adopted to address sexuality. Most articles showed how difficult it is to address the topic in professional practice, from a communication point of view and also regarding interpersonal relationships between patients and health professionals, reaffirming that the sexual health of patients is often overlooked. Studies that addressed the measures taken to remedy the shortcomings showed different degrees of positivity and that it is necessary to train professionals by means of guidance and counseling strategies. Intervention models can be found in the literature.

Conclusion: Sexuality is overlooked in the care of cancer patients. Multidisciplinary care in oncology has to acknowledge this situation and implement, in a joint action, educational and psychosocial support activities so this basic human need is met.

Resumo

Objetivo: Identificar os fatores intervenientes para a abordagem da sexualidade, pelo paciente e profissional, e descrever as estratégias empregadas para a abordagem da sexualidade no cuidado ao paciente com câncer.

Métodos: Revisão integrativa de literatura, baseada em etapas sistemáticas, nas bases de dados e ou bibliotecas eletrônicas: LILACS, PubMed, MEDLINE, IBECs, SciELO, UpToDate, BDeInf. As buscas ocorreram entre dezembro de 2016 a julho de 2017. Critérios de inclusão: estudos com pacientes oncológicos, idade acima de 18 anos; publicados nos últimos dez anos (2007-2017); disponíveis na íntegra; nos idiomas português, espanhol e inglês. Excluídos: teses, dissertações, revisões (sistemática, narrativa e integrativa), artigos de opinião e editoriais.

Resultados: Incluídos 18 artigos, seis artigos referentes a fatores intervenientes e 12 artigos referentes a estratégias adotadas para abordagem da sexualidade. A maioria dos artigos evidenciou a dificuldade com a qual o tema é tratado na prática profissional, nas perspectivas da comunicação e das relações interpessoais entre pacientes e profissionais, reiterando a premissa que a saúde sexual do paciente é, normalmente, negligenciada. Os estudos que versavam sobre as intervenções empreendidas para sanarem as lacunas, demonstraram diferentes graus de positividade e demonstraram que é necessária a capacitação dos profissionais com estratégias de orientação e aconselhamento. Há modelos de intervenção disponíveis na literatura.

Conclusão: A sexualidade é negligenciada no cuidado ao paciente com câncer. A atenção multidisciplinar em oncologia precisa reconhecer esta realidade e empreender, numa ação conjunta, atividades de educação e apoio psicossocial, para que esta necessidade humana básica seja satisfeita pelos pacientes.

Resumen

Objetivo: Identificar los factores que intervienen en la forma en que el paciente y el profesional abordan la sexualidad y describir las estrategias empleadas para abordar la sexualidad en el cuidado del paciente con cáncer.

Métodos: Revisión integrativa de literatura, basada en etapas sistemáticas, en las bases de datos y/o bibliotecas electrónicas: LILACS, PubMed, MEDLINE, IBECs, SciELO, UpToDate, BDeInf. Las búsquedas ocurrieron entre diciembre de 2016 y julio de 2017. Criterios de inclusión: estudios con pacientes oncológicos, de más de 18 años, publicados en los últimos diez años (2007-2017) y disponibles, en su totalidad; en portugués, español e inglés. Excluidos: tesis, disertaciones, revisiones (sistemáticas, narrativas e integrativas), artículos de opinión y editoriales.

Resultados: Se incluyeron 18 artículos, seis artículos referentes a factores intervenientes y 12 artículos referentes a estrategias adoptadas para el abordaje de la sexualidad. La mayoría de los artículos evidenció la dificultad con la cual el tema es tratado en la práctica profesional, en las perspectivas de la comunicación y de las relaciones interpersonales entre pacientes y profesionales, y reiteró la premisa de que, normalmente, la salud sexual del paciente es descuidada. Los estudios que versaban sobre las intervenciones emprendidas para subsanar las lagunas, demostraron diferentes grados de positividad, así como que es necesaria la capacitación de los profesionales en estrategias de orientación y asesoramiento. Hay modelos de intervención disponibles en la literatura.

Conclusión: La sexualidad se descuida en el cuidado del paciente con cáncer. La atención multidisciplinaria en oncología necesita reconocer esta realidad y emprender, en una acción conjunta, actividades de educación y apoyo psicossocial, para que esta necesidad humana básica sea satisfecha en los pacientes.

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Introduction

In the last few decades, as the result of diagnosis and therapeutic progress, cancer has become a chronic disease, and therefore studies that analyze quality of life among surviving patients have become a necessity. That is why different functional aspects of health, for patients undergoing treatment as well as those who survived cancer, have gained greater scientific visibility.⁽¹⁾

The incidence of sexual dysfunction in men and women undergoing cancer treatment varies from 40% to 100%, in which 59% and 79% of men and women, respectively, present an absence or a decrease of sexual activity. There are physical, psychological, and social factors that affect cancer patients and which result in changes in their sexuality, namely: anatomic changes such as colorectal, penis, or testicle removal, mastectomy, and vaginal stenosis; physiological changes such as hormonal imbalance, urinary or fecal incontinence, weight alterations, fistulas, stomata; adverse effects resulting from treatment, among which: nausea, vomit, diarrhea, fatigue and alopecia; self-image, shame, fear, gender social role (a person's behavior, according to the expectations of the group to which this person belongs) and sexual role (the way they show themselves to others and to themselves, sense of being a man or a woman).⁽²⁾

The approach to sexuality with cancer patients is important for many reasons. Before the treatment, patients must be informed about the sexual side effects that are commonly related to cancer treatments in order to help them choose their treatment. During and after treatment, patient-professional communication is essential for the identification and treatment of sexual problems, which can be distressing for patients and affect their quality of life.⁽³⁾ However, this approach is often overlooked by health professionals, which justifies the objectives of our study: to identify the factors that interfere in the approach to the sexuality of patients by health professionals, to describe care and/or educational strategies used by professionals to address sexuality, as well as the impact of these actions in the care of cancer patients.

Methods

This is an integrative literature review, based on the steps proposed by Ganong:⁽⁴⁾ the identification of the topic and preparation of the guiding question; sample selection; categorization of studies; analysis of extracted data; discussion and interpretation of results; presentation of the integrative review and knowledge synthesis.

In the first step, the study questions were made: What are the factors that interfere in the approach to sexuality by health professionals in the care of cancer patients? What are the care and/or educational strategies used by health professionals to address sexuality with their patients and partners? What are the results?

These questions were given the acronym PICO,⁽⁵⁾ where the "population" was made up of cancer patients and health professionals. "Intervention" related to the identification of reasons that affect the approach to sexuality by health professionals and the description of strategies used to help to address the topic with cancer patients. "Comparison" was based on the results obtained, and populations were classified by therapeutic period and follow-up action. "Outcomes" were associated with the identification of intervening factors in patients' sexuality and the characterization of strategies (care and educational) adopted by health professionals to address sexuality.

The second step consisted of choosing keywords, by means of the Health Science Descriptors (DeCS), in a combined way, and the terminological versions in Spanish and English of the terms in Portuguese: neoplasia, sexuality, sexual health, oncology, sexual dysfunction, and education in health; the databases or electronic libraries were: LILACS, PubMed, MEDLINE, IBECs, SciELO, UpToDate, BDENf. The period of article publication went from 2011 to 2017, since the purpose of this study was to find care or educational strategies that were tested empirically, and therefore, this period was the most appropriate because of the evidence of good practices.

The inclusion criteria for articles to be analyzed were: studies with cancer patients aged over 18; published between 2011 and 2017; available in full in Portuguese, Spanish and English. Theses,

essays, reviews (systematic, narrative, and integrative), opinion articles and editorials were excluded (Figure 1).

The instrument created for data collection and analysis featured the following items: publication title, journal, year of publication, type of article, author(s), study objective and outcomes of intervening factors or strategies adopted to address sexuality.

The scientific evidence classification of the selected articles was based on levels of evidence defined by the Joanna Briggs Institute (JBI).⁽⁶⁾ JBI recommends the classification of studies in a pyramidal fashion, in which the bottom is level 5, with expert opinions; followed by level 4, with descriptive observational studies; level 3 with analytical ob-

servational studies; level 2 with nearly experimental studies, and level 1 with experimental studies. Each level is also subdivided into letters. For instance, at level 1 we have: 1a, systematic reviews (SR) of randomized controlled trials (RCT); 1b, SR of RCT and other designs; 1c, RCT and 1d pseudo RCTs⁽⁶⁾

The articles were read by two independent researchers, and the synopsis by another two researchers. After the article eligibility step, the data collection instrument was used, with data being selected from each article according to the objectives of the present study. All researchers participated in the description of data synthesis, and special attention was given to keeping the integrity and authenticity of the original studies.

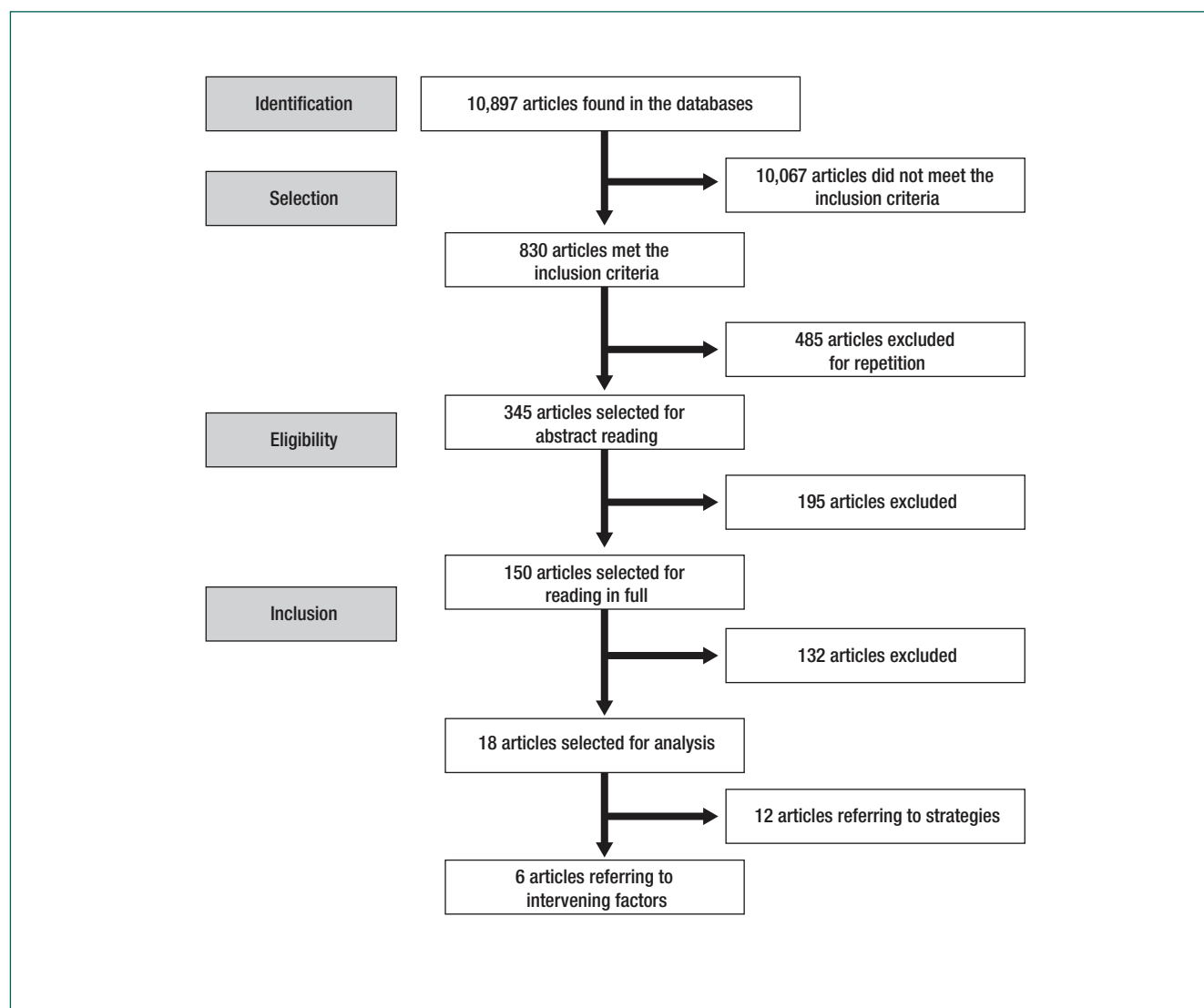


Figure 1. Flowchart of articles selected for the study

Results

After the cross-linking of the selected descriptors, 345 articles were found. Of these articles, 150 were read in full and, at the end, 18 articles were applicable to the review design, six of which referred to intervening factors in the approach to sexuality and 12 articles referred to strategies adopted to address sexuality.

From a time perspective, 15 articles were published between 2011 and 2017, mainly in English (84%), followed by Portuguese (16%). The articles were published in the following countries: Australia, Brazil, Canada, South Korea, United States, Ireland, Island, Turkey. Among the professional fields that produced them, psychology and nursing stood out.

Chart 1 shows a summary of the results selected for answering the first question of the study.

Chart 1. Intervening factors in the approach to sexuality with cancer patients by health professionals

Author(s)/ Journal/Year	Method and Level of Evidence (Joanna Briggs Institute)	Intervening Factors
Lindau et al., Psychooncology, 2011 ⁽⁷⁾	Descriptive Qualitative LE 4b	Barriers to communication about sexuality: Medical appointments restricted to diseases and communication failure between physicians and patients. Barriers to starting a conversation: diagnosis and treatment are considered as a priority; embarrassment and discomfort to address the topic.
Moore, Higgins and Sharek European Journal of Oncology Nursing, 2013 ⁽⁸⁾	Descriptive Qualitative LE 4b	Lack of knowledge and of reference services, work overload, nurses' distorted perception of the appropriate moment to address the issue, feeling of discomfort to discuss it, low education level, age, and ethnic differences.
Junqueira et al., Interface, 2013 ⁽⁹⁾	Descriptive Qualitative LE 4b	Vision restricted to treatment and its side effects, patients' silence about the topic, delegation of dialog to professionals, inefficient professional training, and work overload.
Oskay, Can and Basgol, Asian Pac J Cancer Prev, 2014 ⁽¹⁰⁾	Descriptive Quantitative LE 4b	Health service failures: absence of leaflets and manuals about the effects of treatment on sexual life; absence of a routine of assessment and sexual counseling and lack of professional knowledge on the topic.
Ferreira et al., Rev Latino-Am. Enfermagem, 2015 ⁽¹¹⁾	Descriptive Qualitative LE 4b	Difficulty of creating ties as the result of work overload, institutional bureaucracy, inadequate physical space, and different social interpretations of sex.
Cardoso et al., Rev Rene, 2015 ⁽¹²⁾	Descriptive Qualitative LE 4b	Uncertainty whether the topic can be discussed during treatment, as a result of the priority given to therapeutic issues.

To answer our first objective, it was seen that several factors affect the discussion about sexuality, the perception of patients and of professionals. Six articles that responded to this objective were

found, one of which depicts the vision of patients, whereas five articles showed the vision of health professionals.

In the articles that gathered information of patients, the main reasons for not addressing sexuality were: discomfort, shame, and embarrassment;^(7,12) lack of bonds with professionals;⁽¹¹⁾ medical appointments focusing on signs and symptoms, and sexuality not being a priority;^(7,12) lack of time from professionals;⁽¹¹⁾ inability of professionals to address the topic, by a lack of knowledge or a lack of experience;⁽¹⁰⁾ age and/or gender difference between patients and professionals;⁽⁸⁾ lack of privacy.⁽¹⁰⁾

In the professionals' view, the main barriers were: lack of knowledge, skills and training to discuss and address sexuality;⁽⁸⁻¹²⁾ lack of privacy and time;⁽⁸⁻¹²⁾ sexuality not being a priority in appointments;^(7,9,12) difference of age, gender, religion, culture;⁽⁸⁻¹¹⁾ discomfort, shame;⁽⁹⁻¹¹⁾ bonds with patients.^(9,11) Other barriers were mentioned separately, such as the lack of special services;⁽⁹⁾ professionals' belief that the topic is not considered important by patients;^(8,11) lack of support from colleagues and managers;⁽⁹⁾ professionals not considering it to be their role;⁽⁹⁾ social interpretation of female patients, which is associated with pleasure only being possible for healthy women;⁽¹¹⁾ work overload due to sectorial shifts, institutional bureaucracy and organization.⁽¹²⁾

Chart 2 shows the studies that include strategies to address sexuality.

As for the strategies used by health professionals to address sexuality in the care of cancer patients, two strategies were found: education-assistance aimed at patients and partners, and another one aimed at professional enhancement by means of skill building. Out of the 12 articles related to the objective of intervention identification, nine were related to education and assistance, and three were related to professional enhancement. The target audience of care interventions was mostly women and related to breast and gynecological cancers, with 66% of findings. Two interventions were found for men with prostate cancer, one for patients with colorectal cancer and an intervention for patients with cancer related or not to the reproductive system.

Chart 2. Strategies used by health professionals to address sexuality with cancer patients and their partners

Author(s)/Journal/Year	Method and Level of Evidence (Joanna Briggs Institute)	Intervention design		
		Target population	Intervention procedures	Results
Molton et al., J Psychosom Res, 2008 ⁽¹³⁾	Randomized clinical study LE 1c	n=101 men who underwent radical prostatectomy	Didactic instructions by means of <i>Cognitive-Behavioral Stress Management</i> (CBSM) and a relaxing technique.	The intervention was effective in the promotion of sexual function recovery of patients.
Boonzaier et al., Journal of Psychosocial Oncology, 2009 ⁽¹⁴⁾	Quasi-experimental study LE 2c	n=10 men with prostate cancer	Psychopedagogical and educational manual.	Issues of patients' interest were discussed in group sessions, and this possibility made the experiment quite satisfactory.
Marcus et al., Psychooncology, 2010 ⁽¹⁵⁾	Randomized clinical trial LE 1c	n=304 women with breast cancer	Telephone consultation, specific printed leaflets, progressive relaxation tapes and guidelines of stress management for ongoing breast cancer.	Telephone consultation: inefficient intervention, especially for women with early stage breast cancer. The meaning of the sickness experience was discussed.
Jun et al., Cancer Nursing, 2011 ⁽¹⁶⁾	Quasi-experimental study LE 2c	n=45 women who survived breast cancer	Educational activity, group discussion, counseling, relaxing, role play, movie and pictures screening about couple sexuality.	The intervention increased sexual satisfaction and improved the acceptance of their body image.
Wijler et al., J Canc Educ, 2011 ⁽¹⁷⁾	Quasi-experimental study LE 2d	n=27 women	Web-based support group with a 12-week duration (GyneGals) focused on topics related to sexuality.	Benefits of the intervention: emotional well-being, improvement in the quality of life and sexuality; the anonymity nature of the environment favored discussions.
Schover et al., J Natl Compr Canc Netw, 2013 ⁽¹⁸⁾	Randomized clinical trial LE 1c	n=72 women who survived breast or gynecological cancer	Access to Tendrils website, videos, and a therapist manual with general guidance. Techniques of cognitive behavioral sex therapy	The intervention improved sexual function, satisfaction of women with sexual dysfunction and general quality of life in the post-treatment period. There was a decrease in emotional suffering.
Reese et al., Psychooncology, 2014 ⁽¹⁹⁾	Randomized clinical trial LE 1c	n=23 couples	Telephone consultation.	Improvements in the sexual function for both genders, increased perception of self-effectiveness to enjoy intimacy, and identification of difficulties experienced by a partner who has survived cancer.
Smith and Baron, Clinical Journal of Oncology Nursing, 2015 ⁽²⁰⁾	Quasi-experimental study LE 2c	n=29 nurses	Workshop, role playing, a copy of the American Cancer Society booklet - "Sexuality for the woman with cancer" and weekly e-mails.	Training empowered nurses in their jobs as educators and made it easier to talk about sexual health.
Perz et al., BMC Cancer, 2015 ⁽²¹⁾	Randomized clinical trial LE 1c	n=88 people with cancer n=53 partners	Self-help leaflet and telephone or Skype consultation.	Improvement in sexual satisfaction of participants, effective communication and intimacy within the couple, better sexual flexibility and negotiation regarding the intercourse.
Bober et al., J Sex Med, 2015 ⁽²²⁾	Quasi-experimental study LE 2c	n=37 women	Psycho-educational session, educational materials and telephone consultation.	Increased ability of solving sexual problems and decreased feeling of loneliness.
Jung e Kim, Sexual & Reproductive Healthcare, 2016 ⁽²³⁾	Randomized clinical trial LE 1c	n=24 nurses	Nursing records focused on sexual health care.	Sexual health care improves nursing practice related to sexuality issues and make care services more efficient.
Jonsdottir et al., European Journal of Oncology Nursing, 2016 ⁽²⁴⁾	Quasi-experimental study LE 2c	n=206 nurses and physicians	Workshops and construction of a website for interventions.	Improved knowledge and communication about sexual health issues.

With regard to interventions aimed at health professionals, out of the three selected articles, two were aimed at nurses and one at nurses and physicians.

Among care strategies, we can highlight: on-site groups;^(14,15,17) telephone intervention with previous delivery of printed material;^(15,19,22) online group related to the website;⁽¹⁷⁾ telephone intervention with couples;⁽¹⁹⁾ website;⁽¹⁸⁾ and on-site group with telephone intervention.^(21,22)

The educational strategies found were workshops made of lectures, group discussions, role play, printed material, and e-mails or website purposely constructed for the intervention.^(20,24) Another intervention found was the record of sexual health care.⁽²³⁾

Sexual health care is the record of care services planned and provided to patients with cancer by oncology nurses, with the purpose of making it easier and more efficient. Intervention with sexual health care showed significantly higher levels of sexual health care practice over four weeks of intervention compared to those who provided usual care services to patients with cancer.⁽²³⁾

Regarding workshops, the assessment of this strategy was positive from participants' point of view, since they expressed feelings of empowerment.^(20,24) Role play and e-mails received after the intervention had a positive evaluation. When professionals were submitted to that strategy, they claimed a longer workshop time, especially because

of role playing, to strengthen and improve skills on communication and sexuality approach that they learned.

Discussion

Data from studies which revealed barriers to effective communication about sexual practice among patients with cancer and health professionals showed that there are indeed limiting behaviors to address sexuality in oncology or other fields, as it was shown by another similar study carried out with men and women diagnosed with inflammatory bowel diseases, more often Crohn's disease and ulcerative colitis, thus showing the extent of the problem.⁽²⁵⁾

Barriers arise from implicit suppositions on the topic, both on the part of patients and caregivers. Personal beliefs and values, as well as institutional organization and dynamics act as barriers to the topic discussion. Sexuality has been sidelined in care services and not discussed with patients and their partners. When professionals avoid the topic, patients feel that they are not allowed to address it, thus resulting in silence from both sides.^(26,27)

Generally speaking, there are many aspects to be addressed by patients and caregivers with regard to therapeutic regimen, namely improving their knowledge of the disease, therapy compliance, handling of signs and symptoms and risk situations which lead to reinforcing the biomedical model based on prescriptive practices, in which not all care demands are met.⁽²⁸⁾

There is evidence that health professionals must be prepared to be able to include sexuality in clinical evaluation, leading to a situation in which patients and their partners can feel free to discuss. Sometimes it is necessary to consider that, in order to make sure sexuality is included in discussions, the health staff must assign members to this task, reducing risks of personal conflicts, skills and beliefs becoming barriers.⁽²⁴⁾

Data collected from studies about strategies to approach sexuality and effective communication about sexual practice among patients with cancer and health professionals showed that all strategies

found had a positive feedback from participants. Some studies^(14,16,17) concluded that interventions should be subject to minor adjustments, implemented with treatment underway or not, such as a longer intervention time or the addition of other strategies to promote a long-term impact of the adopted interventions.⁽¹⁸⁾

Marcus et al.⁽¹⁵⁾ inferred that the printed material, although widely used by participants, did not have a great effect when compared to telephone consultations.^(29,30)

The literature has pointed that interventions based on couples were more efficient to improve their communication, to reduce psychological suffering and to enhance the relationship functioning.⁽³¹⁾

Interventions based on couples were effective to promote communication, sexual adjustment and functional relationships with a better understanding of the cancer diagnosis within couples, whereas interventions based on individuals were more effective to improve the results than in group approaches and in the group combined with individual intervention.⁽³⁰⁻³²⁾

With regard to the tools used to train professionals, a long-lasting prospective response was found in the behavior of nurses who were submitted to professional enhancement, increasing the number of nurses who started a discussion about sexual health before patients had started their treatment, and professionals reported that they had gained enough knowledge, proper training and felt more confident in their ability to address the topic.⁽²¹⁾ However, even though the improvements had been reported in the communication of sexual health problems with patients over time, the frequency of these discussions remained below to what is considered acceptable, despite great efforts, since most participants did not reach the goal of discussing sexual health issues with more than 50% of their patients.⁽²⁴⁾

A model of sexual counseling can be a useful tool to improve nurses' skills. Over the last decades, several models have been developed with different objectives and have been instruments capable of providing help throughout the nursing process, such as the assessment of the sexual function and its practice, and the interventions to manage problems found.⁽³³⁾

Mick⁽³⁴⁾ found ten strategies so that oncology nurses can address sexuality with their patients. Such strategies are described as: how to use specific practice standards to make sure the assessment needs of patients are met; to understand sexuality and its assessment in quality of life; to ask broad questions; to encourage patients to ask questions and explore their sexual concerns; and to be an objective listener, avoiding suppositions about the importance of sexuality and intimacy, regardless of the diagnosis and cancer treatment.⁽³⁴⁾

Health professionals play a key role in the reworking of sexuality and sexual life adjustment of patients with cancer. Multidisciplinary care in oncology has to acknowledge this situation and implement, in a joint action, educational and psychosocial support activities, so that this basic human need is met.

Conclusion

The findings of the present study showed a difficulty in addressing the topic in professional practice, both from patients and professionals' perspectives, who are not always ready for this task. Barriers found by patients and professionals related to sexuality were mainly found in the ineffective communication about the topic, lack of dialog and opportunity, focus on the cancer diagnosis, lack of a standardized script to address the topic, among others. Strategies to address sexuality found in the literature varied, including some traditional ones, such as on-site programs and the use of printed leaflets, and active methodology for education and communication, with small group dynamics, simulations, telephone consultations and websites. It was also observed that systematic professional and multidisciplinary actions to assess the sexual function and to provide counseling aimed at their sexual health produce favorable results compared to the use of different strategies.

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