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# REVISIONES

### The most unmet needs on Gynecological and Breast Cancer Survivors, A Systematic Review

Las necesidades más insatisfechas en sobrevivientes de cáncer ginecológico y de mama, una revisión sistemática

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#### ABSTRACT:

Introduction: The complexity of treating gynecological and breast cancer causes unmet needs for survivors. This systematic review aimed to identify the most unmet needs of gynecological and breast cancer survivors from the available evidence.

Method: Researchers searched the electronic databases PubMed, Cochrane, CINAHL, Ebsco Host, and Science Direct with predetermined criteria. The keywords used were combinations of "gynaecologic\* cancer" OR "gynaecologic\* cancer survivors" OR "breast cancer" OR "breast cancer survivors" AND "unmet needs." A systematic review was made using PRISMA, the critical appraisal was carried out with the JBI instrument, and bias analysis was carried out using the Robvis Tool.

Results: There are 12 selected articles. The two highest unmet needs domains for gynecological and breast cancer survivors are the health system information and psychological domains.

Conclusions: Nurses and other health workers must pay attention to implementing holistic care to meet the various needs of gynecological cancer survivors, including health system information and psychological domains.

**Keywords:** breast cancer, cancer survivors, gynecology, needs, systematic review.

#### **RESUMEN:**

Introduccion: La complejidad del tratamiento del cancer ginecológico y de mama genera necesidades insatisfechas para los sobrevivientes. Esta revisión sistemática tuvo como obietivo identificar las necesidades más insatisfechas de las sobrevivientes de cancer ginecológico y de mama a partir de la evidencia disponible.

Método: Los investigadores realizaron búsquedas en las bases de datos PubMed, Cochrane, CINAHL, Ebsco Host, Science Direct con criterios electrónicos predeterminados. Las palabras claves usadas fueron combinacion de " cáncer " ginecológico \*"O" sobrevivientes de cáncer ginecológico \*" O " cáncer de mama" O " sobrevivientes de cáncer de mama" Y " necesidades insatisfechas ". Se realizó una revisión sistemática mediante PRISMA, la evaluación crítica se realizó con el instrumento JBI y el análisis de sesiones mediante la herramienta Robvis.

**Resultados**: Hay 12 artículos seleccionados. Los dos dominios de necesidades insatisfechas más importantes para los sobrevivientes de cáncer ginecológico y cáncer de mama son el dominio de informacion del sistema de salud y el dominio psicológico.

**Conclusión**: Las enfermeras y otros trabajadores de la salud deben prestar atencion a la implementacion de una atención holística para satisfacer las diversas necesidades de los sobrevivientes de cancer ginecológico, incluidas las necesidades de información del sistema de salud y los dominios psicológicos.

**Palabras clave**: cáncer de mama, sobrevivientes de cáncer, ginecología, necesidades, revisión sistemática.

## INTRODUCTION

Cancer is a non-communicable disease that ranks as the second leading cause of death in women (14%) <sup>(1)</sup>. Especially in developing countries, the highest cancer cases in women are breast and gynecological <sup>(1,2)</sup>. Breast cancer cases even reached 1.7 million and deaths in 500 thousand cases, while gynecological cancer reached more than 500 thousand cases and caused death in 265,000 survivors. Furthermore, another astonishing fact is that 90% of deaths in gynecological cancer patients occur in developing countries <sup>(1,3)</sup>. The number of cases is in line with the amount of attention needed by survivors of gynecological cancer and breast cancer, especially related to improving survivors' quality of life <sup>(4)</sup>.

Quality of life is one of the goals of cancer survivor care <sup>(5,6)</sup>. Quality of life in survivors is certainly related to the course of the disease and the effects of primary therapy undertaken by survivors, such as side effects of chemotherapy, radiotherapy, and surgery/operative <sup>(7)</sup>. Survivors of gynecological and breast cancer experience physical and psychological effects and other multidimensional aspects <sup>(8,9)</sup>. Psychological effects experienced by survivors, such as anxiety, depression, and fear of relapse, also decrease the quality of life of survivors of gynecological cancer or breast cancer (10,11).

The complexity of the disease and cancer treatment forms a variety of needs for survivors of gynecological cancer and breast cancer, including biological (physical), psychological, social, cultural, and spiritual needs during and after treatment <sup>(12,13)</sup>. If these needs are not met, it is known as "unmet needs," which will impact the survivor's quality of life <sup>(14,15)</sup>. The more unmet needs, the worse the quality of life for gynecological cancer survivors <sup>(6,16–18)</sup>. Therefore, to improve survivors' quality of life, one way to be pursued is to minimize unmet needs <sup>(9,13,16,17)</sup>.

Various studies state that the unmet needs of gynecological cancer survivors and breast cancer consist of six types: existential survivorship, comprehensive cancer care, information, relationships, and others <sup>(17,19)</sup>. Furthermore, the factors influencing unmet needs include age, educational status, income, cancer location, treatment options, cancer stage, recurrence, and sources of information <sup>(20,21)</sup>. This systematic review aims to determine the unmet needs most often experienced by survivors of gynecological cancer and breast cancer based on the results of previous studies.

# METHODS

This study is a study with a systematic review design. Researchers used several electronic databases as data sources: Science Direct, Cochrane Library, Ebsco, Pubmed, ProQuest, and CINAHL. Researchers searched articles based on keywords, namely unmet needs, gynecological cancer, breast cancer, and survivors. The selection of articles in this systematic review uses the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) procedure <sup>(22)</sup>. Researchers set several inclusion criteria in the selection of research articles, namely as follows:

1. Types of research: cross-sectional, RCT, quasi-experimental, cohort, and review articles.

2. Type of respondent: The population in this systematic review study is gynecological cancer survivors and breast cancer survivors

3. Language and time of publication: English with the year of publication between 2011 and 2022.

4. Type of outcome being measured: unmet needs

The exclusion criteria in this study were research articles with gynecologic cancer survivors and breast cancer survivors with mental disorders.

#### Data management and extraction

After the first researcher got the results of the article screening and deleted the duplicated articles, two researchers (LAN and ARM) conducted a critical appraisal of the selected papers according to the research design of each pieced and determined the risk of bias. Subsequent researchers (YA) resolved the issues if any disagreement arose between those two authors.

#### Evaluation of quality of articles: Critical review of art reports bias assessment

Research criticism was conducted on 12 articles using critical appraisal tools for Joanna Briggs Institute (JBI) Systematic Reviews. The method of research criticism using JBI instruments is carried out based on each research design. A total of nine articles with cross-sectional designs were analyzed with JBI research. One research article with design review, the retrospective study examined using JBI instruments for similar research designs, and one mixed methods article analyzed using JBI for the study. Bias assessment in each piece is done using the Risk of Bias Visualization (RobVis), a tool with high functionality power in reviewing research biases.

### RESULTS

#### **Results of searching the literature**

Researchers conducted an article search on an electronic database reputable to predefined criteria and obtained 838 articles. Furthermore, after deleting the article that is still duplicated, 255 reports were received. The screening was conducted on these articles and investigated 243 words that did not meet the criteria for article selection. A total of 16 full-text articles were further reviewed, but four were excluded

because they did not meet most critical appraisal items with JBI instruments. The total number of articles included in this systematic review study is 12 (Figure 1).

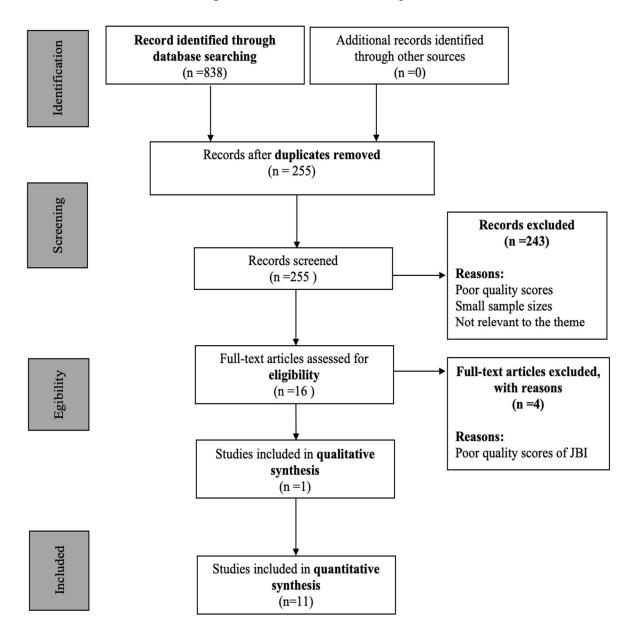


Figure 1: PRISMA Flow Diagram

### **Characteristics of research**

Table 1 contains the characteristics of the studies included in this study.

No.	References	Study Design	Methods	Result
1.	Souza et al., (2017) (23)	Cross- sectional	1214 cancer survivors consisting of 317 gynaecological cancer survivors and 897 breast cancer patients were studied with several instruments, namely EORTC QLQ-C30, PHQ-9 and GAD-7.	The results showed that gynecologic cancer survivors felt that their needs for information related to their disease were not fulfilled, felt the need for psychological support was not met. Breast cancer survivors stated that their unmet need, especially psychological support, was related to their high tendency to experience depression.
2.	Afiyanti et al., (2019) <sup>(19)</sup>	Cross- sectional	298 gynaecological cancer survivors in Indonesia were assessed using the Cancer Survivor Unmet Needs (CaSUN) instrument.	The highest percentage of unmet supportive care needs are informational needs, comprehensive care needs, quality of life needs, existential needs and relationship needs.
3.	Fong & Cheah (2016) <sup>(24)</sup>	Cross- sectional	Researchers interviewed 101 breast cancer survivors using the Supportive Care Needs Survey (SCNS-SF34) instrument.	The highest percentage of unmet supportive care needs is health system and information. The increase in the percentage of unmet needs is related to the age of survivors who are less than 60 years old, are undergoing active treatment, have a high level of education and are not working.
4.	Graf et al., (2020) <sup>(25)</sup>	Cross- sectional	Researchers took data on a total of 771 gynaecological or breast cancer survivors with the Supportive Care Needs Survey (SCNS-SF34) instrument.	The highest unmet care support needs are psychological needs which are influenced by attachment anxiety. Increased attachment anxiety will cause an increase in unmet supportive care needs.
5.	Galvez et al., (2021) (12)	Cross- sectional	Researchers interviewed 396 breast cancer survivors using the	The largest percentage of this type of unmet needs includes two domains, namely health systems and

Table 1:	Description of studies	included in the s	systematic review
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			Supportive Caro	information and the domain
			Supportive Care Needs Survey (SCNS-SF34) instrument.	of psychological needs.
6.	Chou et al., (2020) <sup>(26)</sup>	Retrospective study	Researchers studied 1129 breast cancer survivors. The information collected is related to basic data and questionnaires related to unmet needs.	Unmet needs for survivors who have just been diagnosed with cancer, the highest is the need for information. Cancer survivors who are in the terminal phase have high unmet needs related to psychosocial support.
7.	von Friederichs & Denyse (2012) <sup>(13)</sup>	Mixed methods	Researchers conducted in-depth semi-structured phone interviews on 137 breast cancer survivors.	Unmet needs for respondents, namely breast cancer survivors, are information needs (related to disease, prognosis and series of therapies) as well as needs related to social support, especially from fellow survivors and needs related to health services.
8.	Park & Hwang (2012) <sup>(17)</sup>	Cross- sectional	The number of respondents in this study was 1,250 people. Researchers interviewed respondents with three instruments, namely the Supportive Care Needs Survey, Functional Assessment of Cancer Therapy- Breast cancer instrument and the Beck Depression Inventory.	Unmet needs that occur in respondents are the domain of the health service system and needs related to information. Unmet needs are related to the incidence of depression. Breast cancer survivors for three years had higher unmet needs related to psychological support and information needs compared to breast cancer survivors for more than five years.
9.	Wong et al., (2020) <sup>(21)</sup>	The prospective, observational design	Respondents in this study were 740 people.	The highest level of unmet needs is in the physical and daily living domain, psychological domain, health system and information domain. Unmet needs are influenced by the type of care they receive, the level of morbidity, distress, and the presence or absence of psychosocial

				care.
10.	Akalin & Pinar (2016) <sup>(27)</sup>	Review Article	An overview of the literature	Unmet needs in gynaecological cancer survivors include needs that are not met physically, socially, financially, emotionally and psychosocially and spiritually.
11.	Wang et al., (2018) <sup>(28)</sup>	Cross- sectional	A total of 264 respondents who were breast cancer survivors were assessed using the 34-item Supportive Care Needs Survey Tool (Chinese version) (SCNS- SF34-C) related to the assessment of unmet needs.	The highest unmet needs are the needs related to information about the health care system for breast cancer survivors.
12.	Seland et al., (2021) <sup>(9)</sup>	Cross- sectional	This study has a total of 92 respondents. Researchers used the National Comprehensive Cancer Network Distress Thermometer Problem List (NCCN DTPL) instrument.	More than 50% of respondents stated the distress they experienced and more than half of the respondents also stated unmet needs related to rehabilitation services. These unmet needs are especially felt in respondents who are experiencing distress.

### Unmet needs on Gynecological and Breast Cancer Survivors

Most of the research in selected articles in this systematic review study shows that the highest unmet needs in gynecological and breast cancer survivors are informational and psychological support (9,12,13,17,19,21,23-28). This need is not only felt in survivors of gynecological and breast cancer in the early period of diagnosis but also felt as an unmet need from the beginning of diagnosis when the treatment period until the rehabilitation, terminal, and palliative phases (9,17,26).

The effects of unmet needs for informational and psychological support are increased distress ss, a tendency to experience depression, and decreased quality of life <sup>(9,21,23,25)</sup>. Other impacts include increased morbidity felt by survivors by worsening physical symptoms and complaints of treatment side effects <sup>(21)</sup>. Unmet needs related to health care system information include unclear information about the disease, treatment procedures, therapeutic effects of the series of therapies, and the planning of subsequent treatments <sup>(13,26,28)</sup>. Unmet needs related to social support the highest desired is social support from fellow survivors <sup>(13,25)</sup>.

#### Risk of bias

Researchers tested the risk of research bias on selected articles using the Robvis tools. Most low-risk article essays bias well across the parameters of Robvis software. Figures 2 and 3 show the risk bias summary of the selected article (Figure 2) (Figure 3).

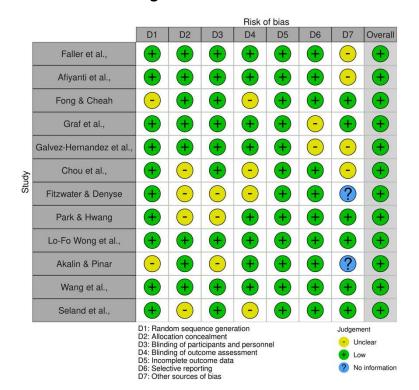
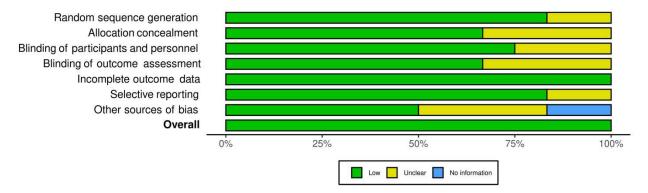




Figure 3: Summary plot



# DISCUSSION

Gynecological and breast cancer survivors have long-term and complex treatment <sup>(29,30)</sup>. The disease's complexity and treatment effects result in the emergence of various multidimensional needs in survivors of gynecological cancer or breast cancer <sup>(11)</sup>. These needs must be met to improve survivors' quality of life <sup>(25)</sup>. The condition of not optimal comprehensive care has caused various unmet needs for gynecological and breast cancer survivors <sup>(11)</sup>. Selected articles in this systematic review of unmet

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needs have been criticized using analysis with the Joanna Briggs Institute (JBI) instrument with good results and a low risk of bias in the RobVis instrument.

Most of the selected articles in this systematic review study state that the highest unmet need in gynecological and breast cancer survivors is the need for information <sup>(12,13,17,21,23,24,26–28)</sup>. Survivors whose information needs are met will be able to utilize self-management strategies and support other survivors to improve their well-being. This explains that this fulfilled information need is related to survivors' quality of life <sup>(4,23)</sup>. Information needed by gynecological and breast cancer survivors includes diagnosis/cancer, the possibility of recovery/recovery, course of disease/prognosis, medical therapy options, and risk of treatment side effects <sup>(12,13,26)</sup>. Other information includes an explanation of laboratory examination results and additional support, counseling with professionals, information on efforts to prevent recurrence and complications, and the benefits and disadvantages of each therapy undertaken <sup>(23,24)</sup>.

Survivors with unmet information needs are associated with increased depression and anxiety <sup>(17,23)</sup>. Other research shows that unmet needs related to this information become the most common / the most ranked. This indicates that there is dissatisfaction experienced by survivors, obstacles in delivering information, and a lack of communication between health teams and survivors <sup>(12,17)</sup>. Survivors who are dissatisfied or feel unmet information need to express a desire for more comprehensive information, second opinion, and other specific information <sup>(12,13,23)</sup>.

Unmet needs related to this information not only occur in survivors of gynecological and breast cancer in the early stages but also occur in survivors of the end stage, it implies a high need for this information about the condition of survivors based on the course of the disease (stage of cancer experienced) <sup>(17,24)</sup>. The longer a survivor has cancer / the higher the scene is not directly proportional to the knowledge/information that the survivor has longer has cancer / the more increased the location is not directly proportional to the knowledge/information that the survivor has longer has cancer / the more increased the location is not directly proportional to the knowledge/information that the survivor has <sup>(17)</sup>. Most survivors claim to seek their lead over the internet, not even getting an explanation related to treatment, especially a second opinion <sup>(13)</sup>. Unmet needs associated with this information occur in survivors of gynecological and breast cancer in various parts of the world, such as most regions of Asia, Mexican, and Latin America <sup>(12,28)</sup>. The information needs meeting for survivors to increase their involvement in care, risk assessment, understanding of screening and care, and even improving the quality of care outcomes <sup>(27)</sup>.

The highest unmet needs are the psychologic and psychosocial domains associated with fears of recurrence, worsening of symptoms, or side effects of treatment <sup>(9,12,17,21,25,26)</sup>. In one of the studies, researchers stated that unmet needs related to this psychological domain are higher in survivors who experience recurrence and survivors who are already in a terminal condition <sup>(25)</sup>. Concerns facing death, the future, depression, and fear of leaving family and others lead to emotional and mood instability and worsening quality of life. One of the efforts to reduce this unmet psychosocial need is to provide adequate information about what survivors want and need to know in counseling and assessment related to this domain so that this need is no longer neglected <sup>(12,25,26)</sup>. Of course, you can also use support groups of fellow survivors to get information based on the experiences of other survivors <sup>(13,17,21)</sup>. Findings from this systematic review indicate that the two highest unmet needs domains in survivors of gynecological and cervical cancer are related to health care

information and psychological/psychosocial domains, where one of the efforts to prevent and or overcome it is by providing adequate information.

Information on survivors includes clear explanations of disease diagnosis, treatment, and treatment, nutrition, psychological, and sources of financial assistance that survivors can access <sup>(26)</sup>. Some alternative solutions that can be considered and further researched effectiveness include interdisciplinary training of therapeutic communication skills, operational standards of procedures regarding providing information, assessment of the information needed to package information related to the survivorship care plan, quality supervision or quality of nursing care services and health care teams in general. In addition, the use of technology is also needed in efforts to improve care services. The limitations of this systematic review study are that the selected articles are still heterogeneous from the number of respondents, and the cancer stage is not included in the inclusion criteria.

## CONCLUSIONS

The highest unmet needs for gynecological and breast cancer survivors are informational and psychological needs. Informational needs related to disease prognosis, treatment, nutrition, side effects, and potential recurrence. Furthermore, survivors also need psychological support. This finding implies the need for further research on effective techniques of survivor care, especially in terms of providing adequate information and psychological support to improve the quality of holistic nursing care for gynecological and breast cancer survivors.

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